How can the HIV counselling programme in the Una district, Himachal Pradesh State, Northern India, be made more effective? An appreciative inquiry by frontline counselling staff and high-risk clients.

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ABSTRACT

Human Immunodeficiency Virus (HIV) counselling of high-risk groups (HRGs) is an under-researched area in India. HRGs include female sex workers (FSWs), men who have sex with men (MSM), injecting drug users (IDUs), Hijra/transgender people (HTG), single migrant men (SMM), and long-distance truckers (LDTs) have a higher HIV prevalence compared to adult HIV prevalence in India. HRGs are often at risk because of a number of social, organisational, and management factors. These barriers affect how HRGs access and engage with the Indian HIV counselling programme.

The HIV counselling programme is the key point of access or entry to HIV diagnosis and treatment for HRGs. HRGs are the key clients for the programme. Internationally, studies indicate that it is an effective measure to ensure regular HIV testing, reduce the risk of transmission, and improve the health and well-being of HRGs. This study investigated the research question *"How can the HIV counselling programme delivered in Una district, Himachal Pradesh state, Northern India, be made more effective?"* Given that they are key clients this study adopts the perspective of HRGs and also the perspectives of the counsellors associated with the HIV counselling programme. The first sub-question explored current knowledge about the evolution of the Indian HIV programme and how that has shaped effectiveness today. As the empirical part of the study, research sub-questions two and three focused on engagement with the co-researchers as a means of exploring the effectiveness of the HIV counselling programme through their lens.

The study adopted a participatory research methodology, specifically appreciative inquiry (AI), for eliciting the perspectives of HRGs and frontline counselling workers (FCS), acknowledging their critical roles as clients and workers. AI further became the means of identifying strengths-based solutions to improve a public health programme (PHP) and bringing of positive change within organisational settings. The AI phases of the research process—called the 4D phases—were discovery, dream, design, and delivery. HRGs and FCS, who conducted this AI through focus group discussions (FGDs), have been referred to in the study as ‘co-researchers’ (CRs). Like other participatory research methods, AI follows a strengths-based approach. However, it is distinguished by its capability in providing a space for the voices within an organisation, in this case that of FCS and HRG clients; and to address an organisational issue, that of HIV counselling programme effectiveness.

The findings are presented in three chapters. The first findings chapter represents the discovery of the organisational, management factors that affect the implementation and success of HIV testing and counselling programmes in Una. The issues raised by CRs in relation to the resources and infrastructure required, and policies and procedures necessary for the effective operation of the programme are examined.

The next chapter of discoveries is from a sociocultural lens focusing on the neglected cultural and social factors that affect the accessibility and uptake of counselling services. It revealed that the programme ignored the belief systems of HRGs and often overlooked the personal and social implications of being associated with an incurable and stigmatised illness which often leads to denial of a HRG from a positive diagnosis or even defiance towards accessing HIV counselling services. The final findings chapter revisits the 4Ds as a guide to developing an effective HIV counselling programme, concluding with a discussion on how it would be implemented in a real setting.

The study findings have implications for transformed approaches to addressing the challenges faced by HRGs when accessing the HIV counselling programme in Una. Policy and programme recommendations include the need for a more contextualised and social determinants-based approach; promotion of indigenous ways of counselling; and inclusion of CRs’ perspectives in planning, development, and operations. The study contributes to the growing body of literature that uses AI as a methodology and examines the issues of people at risk of, or living with, HIV/AIDS. It paves a valuable path for a culture of transformation, creating an environment for positive change and suggesting a wellbeing centred model for Indian HIV counselling programme.

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GLOSSARY AND ABBREVIATIONS

4D	4 stages of AI – Discovery, Dream, Design and Destiny
AI	Appreciative Inquiry
AIDS	Acquired ImmunoDeficiency Syndrome
ART	Anti Retroviral Therapy
Baba	Local word for a Hermit (Ascetic)
Bhabi	Local word for a sister in law but used to refer certain FSWs
CMO	Chief Medical Officer
CR	Coresearchers
DAPCU	District AIDS Prevention and Control Unit
Dera/Gharana	Network for transgenders, crossdressers and gay men
FCS	Frontline Counselling Staff
FGD	Focus Group Discussion
FSW	Female Sex Worker
GFATM	The Global Fund to Fight AIDS, Tuberculosis and Malaria
HCTS	HIV Counselling and Testing Service
Hijra/Kinner	Local word for transgender
HIV	Human Immunodeficiency Virus
HPSACS	Himachal Pradesh States AIDS Control Society
HRG	High Risk Groups
ICTC	Integrated Counselling and Testing Centre
IDU	Injecting Drug Users
IT	Information Technology
LDT	Long Distance Truckers
MoHFW	Ministry of Health and Family Welfare
MSM	Men who have Sex with Men
NACO	National AIDS Control Organisation
NACP	National AIDS Control Programme
OST	Opioid Subsitute Therapy
Panthi/Kothi	Local word for MSMs
Peer	NGO Field staff who is also a member of HRG community
PLHIV	People Living with HIV
PR	Participatory Research
SMM	Single Migrant Men
UNAIDS	The Joint United Nations Programme on HIV and AIDS
VCT	Voluntary Counselling and Testing
WHO	World Health Organisation

ATTESTATION OF AUTHORSHIP

“I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.”

Signed:

Balakrishnan Sukumaran Nair

February 28, 2023

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Knowledge is, in the end, based on acknowledgement.
Ludwig Wittgenstein

Dear Reader, I acknowledge the desire to have this communication taken seriously. My life has been a series of spontaneous changes, as has my PhD. It took me nearly a decade to complete this endeavour with many happy and sad days, a mosaic of experiences and emotions, and moments of laughter, tears, triumph, defeat, frustration and fulfilment.

I am indebted to those who waited for my PhD's conclusion and those who left me for some reason. Though he is no longer with us, I pay homage to Papa, who always believed in me, even when I didn't believe in myself. His words of wisdom, unwavering support and guidance helped me become the person I am today. I am forever grateful for the memories we shared together, and I will always hold you in my heart. I honour my Amma, whose prayers and nags kept me grounded. My daily conversations with my brother, Gopal, kept me sane, especially with my philosophical dilemmas. A big thanks to my sister-in-law, Anu, for her food and jokes and to my in-laws, Achhan, Geethamma, Lakshmi and Jayesh and my extended family. Finally, a tender thanks to the showers of hugs and kisses from my kids, Arnav and Harini, and my niece, Lakshya, that kept me thriving.

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ETHICS APPROVAL

The Auckland University of Technology Ethics Committee (AUTEC) approved this research on November 29, 2012. AUTEC Reference number: 15/387.

The Chief Medical Officer's office at the Una District Hospital, Himachal Pradesh, India approved this research on December 22, 2015, under Research Approval Number: HFW-Una (B) 15/2015 – 17242.

DEDICATION

A poem that my grandfather and father liked the most.

The heights by great men reached and kept were not
attained by sudden flight, but they, while their
companions slept, were toiling upward in the night.

by Henry Wadsworth Longfellow.

CHAPTER I – INTRODUCTION

> *Even as poverty severely inhibits the socio-economic progress of developing countries, the alarming spread of HIV/AIDS drains their productive capacities. The correlation between HIV incidence and poverty is too compelling to ignore.*
>
> Late Sh. Atal Bihari Vajpayee, The ex-prime minister of India
> (Dass, 2004, p. 294)

1.1. Introduction

Human Immunodeficiency Virus (HIV) counselling of high-risk groups (HRGs) in north India is an under-researched area. HRGs, which include female sex workers (FSWs), men who have sex with men (MSM), injecting drug users (IDUs), *hijra*/transgender people (HTG), single migrant men (SMM), and long-distance truckers (LDTs), are often placed at risk by a range of sociocultural norms and processes (Meehan et al., 2015; National AIDS Control Organization [NACO], 2020). These factors affect how HRGs access and engage with the Indian HIV counselling programme. Research from other countries demonstrates that counselling is an effective measure in ensuring regular HIV testing, reduced risk of HIV transmission, and improved health and well-being of HRGs (Mehra, de Pee and Bloem, 2017). It is the key point of access to HIV diagnosis and treatment for HRGs. Typically, HIV counselling is a process by which a counselling staff elicits and gives information to a client and their family members for the prevention of HIV transmission (Joint United Nations Programme on HIV/AIDS [UNAIDS] Technical Update, 1997), explicitly concentrating on emotional and social issues related to possible or actual infection with HIV and Acquired Immunodeficiency Syndrome (AIDS) (Bor, Miller and Goldman, 2013). However, there is a lack of evidence in India regarding the significant barriers to HIV counselling and other related services, such as treatment, faced by HRGs, and how these barriers contribute to higher transmission (Meehan et al., 2015).

This study used a participatory research methodology, specifically appreciative inquiry (AI), to explore the effectiveness of the HIV counselling programme for HRGs of the Una district in Himachal Pradesh, northern India. Central to the study was an exploration of how the complexities posed by a range of sociocultural factors experienced by HRGs while accessing the counselling programme help define health choices and outcomes in light of their risk of HIV infection or AIDS. The process of engagement using AI provided a space for HRGs and frontline counselling staff (FCS) to share their perspectives (acknowledging their role as co-researchers in this study) to identify strengths-based solutions to improve programme effectiveness.

The study investigated the programme's effectiveness whilst contextualising it, considering the epidemiology of HIV in India and the public health policy and system. By adopting a critical lens, AI allowed for exploring power and inequality at a micro-level, exposing deeply entrenched social determinants; and at a macro-level of socio-political and healthcare processes (Guijt, 2008; Royal, 2014). Guided by its roots in critical social research (Grant and Humphries, 2006), using AI (Ludema and Fry, 2008; Whitney and Cooperrider, 2011) the research aimed to provide programme recommendations that could improve the health outcomes of HRGs in Una.

This chapter presents an overview of the research topic and the rationale and aim of the study. It offers insight into the AI methodology and its underpinning critical social research paradigm that informed the design and analysis of the study. The process of developing the research focus is described, with the personal and cultural preunderstandings of the researcher examined. Finally, the chapter provides key definitions, the significance of the study, and an outline of the thesis.

1.2. Background and Rationale

HRGs are vulnerable to contracting sexual diseases due to social and economic challenges, and face potential barriers to HIV counselling and treatment (UNAIDS, 2008). These factors create barriers to accessing health care services and, thus, HRGs may present for care later than the general population (Grove et al., 2021; National AIDS Control Organisation [NACO], 2016). The Indian Integrated Biological and Behavioural Surveillance (IBBS) 2014-2015 reported that a significantly higher percentage of HRGs in the working-age population (15–49 years) were engaged in unprotected paid sex, unprotected anal sex, and used the same needles for injecting drugs (NACO, 2015b)—all high-risk activities that can result in contracting HIV. Most people living with HIV (PLHIV) are part of HRGs or associated with HRGs (Ministry of Health and Family Welfare, [MoHFW], 2019). The current prevalence is 6.26% for IDUs, 3.14% for HTG, 2.69% for MSM, and 1.56% for FSWs, which is higher compared to most middle-income countries. Although the adult HIV prevalence for India is low (0.22%) (MoHFW, 2019; UNAIDS, 2018), due to a high population, it equates to 2.1 million PLHIV, which is the third-highest number globally (UNAIDS, 2020).

Although prevalence varies among different HRG subgroups, rates are significantly higher when compared to the general population of India (Tanwar et al., 2016; UNAIDS, 2019a, 2019b). Subsequently, several Indian states with a higher HRG population have tended to show a higher adult-HIV prevalence. Since the start of the epidemic, high prevalence has been seen in southern states; whereas several central, northern, and western states, including Himachal Pradesh, have shown a stable to rising trend (NACO, 2019). This gradual increase, combined with increased migration from southern states, has contributed to new pockets of high HRG activities in northern states in recent years (NACO, 2019). Despite the higher prevalence, significant vulnerabilities, and the risk that HRGs offer to the general population, the HIV counselling programme has given little attention to the factors that impact their health outcomes. Consequently, there has been a lack of research on HIV prevention services in India, especially on its HIV counselling programme.

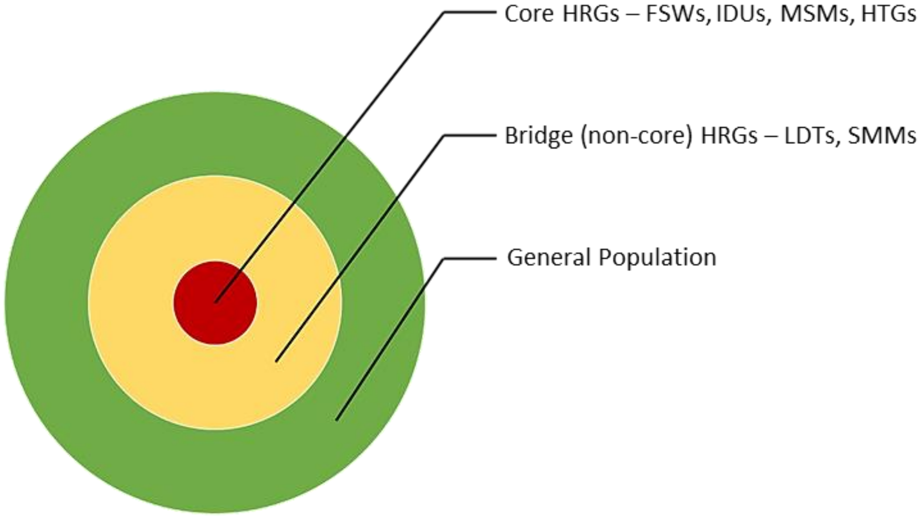
The marginalisation and vulnerability of HRGs is evidenced in the HIV epidemiological patterns for these populations, wherein a significant subset of these groups has a lower life expectancy than the general populations, even after receiving treatment (Teeraananchai et al., 2017). Of the 31,952 deaths due to AIDS-related causes in 2021 and 57,560 newly infected with HIV, most cases were associated with high-risk activities (NACO, 2021). Since the emergence of the epidemic in India in 1986, HRGs have accounted for the majority of new HIV infections annually, which suggests that HRGs are more vulnerable because of the socio-economic determinants that shape their risk environments (Rao, 2016). HRGs also account for most new infections in the working-age population, which has implications for productivity and household income (MoHFW, 2019), especially in India, where most high-risk sexual practices are associated with breadwinning (Dandona et al., 2006).

Despite the recognised vulnerability of HRGs in India, it was within the last 20 years that the programme identified the MSM, IDUs, FSWs, and HTG subgroups as ‘central to’ or ‘at core of’ the spread of HIV (see Figure 1.1.). As Figure 1.1 shows, the transmission of HIV reaches beyond HRGs to the general populations through bridge-HRGs; in particular, LDTs and SMM who are at greater risk often through paid sex away from home (NACO, 2017a).

The HIV and AIDS (Prevention and Control) Act, 2017, portrayed HIV as a ‘concentrated epidemic’ in India prevalent amongst the core-HRGs (Government of India, 2017). A concentrated epidemic is where a population, usually a subset of a larger grouping, are experiencing a higher prevalence rate (UNAIDS, 2013a). Due to a concentrated nature and a low total adult prevalence, Indian states do not regard HIV as an issue among the general populace; thus, often receive less public funding compared to other mainstream PHPs.

Figure 1.1.

HIV Transmission Relationship Between HRGs and General Population (NACO, 2017a)



In India, this concentrated epidemic presented in a high prevalence among IDUs (7.2%), MSM (7.4%), and FSWs (5.1%), and low prevalence among the general population (0.34%). These rates have been relatively consistent from 2008 to 2020 (NACO, 2008, 2021). The risk associated with core-HRGs extends to LDTs and SMM, who are estimated to have an HIV prevalence rate of 0.86% and 0.51%, respectively (MoHFW, 2019), and NACO (2015) suggested that these groups play a crucial role in spreading HIV infection from core-HRGs to the general population.

There is a need to further assess the vulnerability of bridge-HRG, LDTs and SMM, at risk of contracting HIV due to their higher mobility in search for employment and whose sexual health behaviours may contribute to the HIV epidemic in India. NACO (2007) identified these high-risk heterosexual or bisexual men as another critical population in developing the HIV epidemic in India. These bridge-HRGs were identified based on the nature of their work and mobility, and their sexually active age. Additionally, these men live away from their regular partners for extended periods, predisposing them to transactional sex with core-HRGs. Thus, LDTs and SMM constitute a sizeable proportion of clients of sex workers. Since these groups serve as conduits of infection from core-HRGs to the general population, they are also known as bridge-HRGs (NACO, 2007c). While the programme reported that India has around 3.26 million core-HRGs, the bridge-HRGs were estimated at 10 times the core-HRGs, making them 2% of the population of India (Arumugam et al., 2020; Census, 2019; NACO, 2021).

Overall, the HIV counselling programme recognises that HRGs and bridge groups consistently engage in risky behaviours, placing them at a heightened risk of contracting and spreading HIV (NACO, 2007c, 2021). These vulnerabilities are heightened due to incomplete definitions of risk behaviours that only relate to sexual practice, safe injecting drug use, and seeking healthcare, and ignore their social challenges (Atchison and Burnett, 2016; Fairbairn et al., 2010; Huedo-Medina et al., 2010). Indian HRGs engage in high-risk behaviours in a secretive manner; for example, looking for hidden places to inject drugs, discreetly engaging in transactional sex, or not engaging in HIV care while at the same time managing their social roles of the family workplace and household. These dual roles—social and sexual—resulted from the taboo and stigma surrounding such behaviours (Chellaiyan, Raut and Khokhar, 2018; NACO, 2015; Saggurti et al., 2013). Sociocultural norms of gender and sexuality help to fuel the prevailing stigma attached to HIV, sex work, and same-sex relationships, which becomes a barrier to some HRGs accessing counselling, learning about their HIV status, and progressing into treatment and care (NACO, 2015; Steward et al., 2013; Washington et al., 2014).

1.2.1 HIV Counselling Programme and FCS

The HIV counselling programme in India has demonstrated effectiveness in fostering regular HIV testing, reduced risk of HIV transmission, and improved health and well-being of HRGs. HIV counselling has been the main entry point for Indian HRGs to access HIV diagnosis and treatment and public health care in general. The programme components are pre-test counselling, an HIV diagnosis, followed by post-test counselling. The client is then referred to treatment and support services as needed (NACO, 2016a). Approximately 50 countries that follow the UNAIDS best practice guidelines adhere to a similar process for delivering their HIV counselling services (UNAIDS, 1997).

The first phase of the Indian HIV control programme to set up a surveillance system and ensure access to preventive services began in 1992. The HIV counselling programme was initiated in 1999 (NACO, 2016a) as a part of a strategic shift with a newer aim of reducing the spread and increasing national capacity for a long-term response. For HRGs, it functioned as the key entry point of access for HIV diagnosis and treatment.

Being a signatory to the declaration of commitment on HIV/AIDS in 2001, India has adhered to guidelines laid by UNAIDS to execute its programme for HRGs. Given the reliance on foreign funds, the Indian government has followed UNAIDS strategies focusing primarily on increased testing and treatment (Kates and Lief, 2006). The programme reports use a positivist or post-positivist paradigm to evaluate quality that involves quantitative variables and statistical methods, focusing on measurable outputs as the agents of improving quality (UNAIDS, 2014). These measures ignore essential issues like sustainability, power relations within the programme, views of clients and providers, culture, values, and ethics in broader public health, and even the location of the HIV counselling centre.

Due to their quantitative nature, the progress reports on the Indian AIDS control programme have found it hard to measure the effectiveness of HIV counselling in reducing HIV prevalence (NACO, 2019). Consequently, this gap in evidence has resulted in reduced governmental support to the HIV counselling programme (NACO, 2014; Tanwar et al. 2016). Moreover, the expenditure on HIV counselling services to HRGs internationally has lesser domestic public health funding and primarily relies on the personal funds of the clients (Ekstrand et al., 2012; Nyblade et al., 2019).

At the district level, the HIV counselling programme is implemented by field workers, referred to in this thesis as FCS. A FCS is either an employee of the district programme or an affiliated NGO associated with the programme, and could be a counsellors, lab staff, pharmacist, nurse, outreach worker, or peer educator. The outreach workers and peer educators work at the NGO level, while NGOs or programmes can employ other FCS. Though less qualified, they are primarily members of the HRG community employed based on their community networks. Every other FCS has a tertiary qualification and/or experience working with HRGs. Those working at the NGOs are contracted for community-based activities and bringing more clients to the programme for counselling, testing, and treatment. Although bearing a high work burden, these workers received lower wages than their counterparts in other PHPs (Sahay et al., 2011; Umesh, 2014).

Several countries, following similar processes for delivering their HIV counselling services (UNAIDS, 1997), report the programme effectiveness in a similar manner (UNAIDS, 2021). Where quantitative data on counselling in India exist, less data are available on the effectiveness of counselling. The HRG related counselling data were also generally not disaggregated from the general population (NACO, 2021). Before 2007, several descriptive studies had attempted to examine the effectiveness of counselling in increasing knowledge of HIV amongst HRGs and in reducing high-risk behaviours (Denison et al., 2008; Hutchinson et al., 2006; Weinhardt et al., 1999). Since 2007, the global research community has shifted their attention towards testing and treatment (Altice et al., 2019; Johnson et al., 2017; Kanters et al., 2017), neglecting HIV counselling. Furthermore, no study directly compares the differential effects of 'only testing' versus 'testing with HIV counselling'—admittedly not easy to do (Hope, Richman and Stevenson, 2018).

Though there has not been an HIV related study conducted in the Una district, seven studies in other parts of India have evaluated the effectiveness of the national counselling programme (Dash et al., 2013; Mehra et al, 2014; Papanna et al., 2012, 2013; Rahbar et al., 2009; Roy and Saha, 2018; Washington et al, 2014). However, six of these studies failed to provide HRG related information. The findings from the seventh study were primarily descriptive and concentrated only on a community outreach programme for FSWs (Washington et al., 2014). The main findings of the study noted that skilled peer educators improved programme performance, maintaining increased condom supply was a helpful structural intervention, and polling booth surveys were more effective in reporting stigmatised behaviours than face-to-face interviews (Washington et al., 2014).

Within the past decade, there has been a slight increase in the number of HRGs visiting testing centres despite the barriers they face (NACO, 2018a, 2021). This increase can be attributed to the recent emphasis of UNAIDS towards focussed testing and treatment for HRGs (UNAIDS, 2018, 2019, 2021). With targeted testing, there has also been an increase in new infection counts in 2018-19 (MoHFW, 2019; NACO, 2018a); perhaps because it identifies cases that justify this epidemic's concentrated nature (UNAIDS, 2018, 2019). In 2021, the new infection counts were even lower, probably due to lesser surveillance and less testing centre visits during COVID-19 restrictions, which may not serve as a good comparison. Significantly fewer Indian

HRGs knew about their HIV status compared to other Asian countries (e.g., Cambodia, Mongolia, Nepal), who also reported a concentrated epidemic (UNAIDS, 2018). These figures imply that fewer HRGs were tested despite targeted efforts, indicating some failings in the programme (Chourase, 2017). Moreover, a targeted effort presented a structural inequality that distinguished HRGs as agents of HIV transmission (Evans, Jana and Lambert, 2010).

Overall, there is a substantial gap in studies in India and other UNAIDS member nations that 1) examine the barriers to the HIV counselling programme for HRGs, at a local and national level, and across subgroups (e.g., FSWs, MSM, IDUs, HTG, SMM and LDTs); 2) investigate the counselling experiences and behaviours of HRGs, and the experiences of FCS; 3) provide approaches to addressing the challenges faced by HRGs when accessing the programme; and 4) endeavour to focus on the determinants of health affecting HRGs in the programme as a priority area for the future policy and practice. This thesis aimed to address these gaps in knowledge by examining the views of FCS and HRGs towards HIV counselling programme, and developing strategies and recommendations for its improvement.

1.2.2 Study Location

The study is located in one district, that of Una, in Northern India, to explore the issue in-depth. It considers this case within the contours of India’s public health and sociocultural context. With a population of 521,000, Una is a densely populated district in Himachal Pradesh state and an industrial and transport hub for the neighbouring states. The district has more than two thirds of the population above the age of 15 years, with higher literacy levels.

The rationale for focusing on district level in India is multifactorial. A district is an administrative division of an Indian state. As of 2021, there are a total of 748 districts across 28 Indian states. The state funds their health care while the programme funds are derived from the federal funds based on the respective state demands. Himachal Pradesh has 12 districts. Being a state with low HIV prevalence, Himachal Pradesh is categorised as low priority state under the HIV programme. Una has been categorised as a high priority district within this low priority state, due to its high seropositivity and being a location for high HRG activity due to its topographical position. This was the reason why Una was chosen as a research location. Further, as the researcher, I also had professional links with the health authorities at Una which provided me with better access to health care and community level services.

This participatory research examines the views of FCS and the HRG clients towards the programme and the factors that decide their risk of HIV/AIDS. Although significant research studies have considered factors that limit healthcare access in HRGs (Balarajan, Selvaraj and Subramanian, 2011; Cowling, Dandona and Dandona, 2014), no research has provided an in-depth assessment of these factors, their interplay with the programme, and the health choices that HRGs make.

1.3. Research Questions and Study Aim

Given the importance of HIV counselling in the management of HIV in India, this study aimed to explore the effectiveness of HIV counselling by focusing on one programme in the Una district, Himachal Pradesh state, northern India. From the perspectives of key clients, the HRGs of Una district, and FCS, the main research question asked was: “*How can the HIV counselling programme delivered in Una district, Himachal Pradesh state, northern India, be made more effective?*”

The three research sub-questions are:

1. How has the Indian HIV counselling programme evolved and how has that shaped programme effectiveness today?

2. What are the views of FCS and HRGs on HIV counselling programme effectiveness?
3. What strategies might evolve from the perspectives of FCS and HRGs, and how could such strategies improve the effectiveness of HIV counselling programme?

The first question considers current knowledge about the evolution of the Indian HIV programme and how that has shaped effectiveness today. Research questions two and three, as the empirical part of the study, focused on engagement with the co-researchers (CRs) for exploring the effectiveness of the HIV counselling programme through their lens. Considering that this research involves empowerment, a subjectivist approach was adopted, actively involving these stakeholders as research partners (Wicks and Whiteford, 2006). Thus, it aimed to present the different viewpoints of FCS and HRGs and the power dynamics these diverse groups face when participating in the programme, their personal lives, their views on HIV counselling in Una, and their ideas on improving the programme.

1.4. Methodological and Theoretical Lens

The Indian HIV counselling programme has been monitored for its quality through regular surveillance and monitoring activities and epidemiological assessments throughout its 23 years of operation (NACO, 2009, 2016). It reports the quality of its counselling programme in terms of the number of clients counselled, number of treatment referrals, and treatment adherence levels (NACO, 2009); where the definition of quality relates to quantitative outputs and associated outcomes. However, the reports neither captures the perspectives of HRG clients towards the programme, nor evaluates their barriers to accessing services. Additionally, there are no reports on the challenges faced by the FCS during programme implementation, or discussions on any new methods that could benefit HIV care. The reports lack justification on the mismatch between the users’ experiences and the reported programme outcomes. There are no guidelines that justify how the reported data show the evidence of effectiveness of HIV counselling programme from the viewpoint of clients and FCS (Sewell, 2022).

‘Programme effectiveness’ is an essential concept in public health management. Effectiveness is described as the ability to produce the desired result (Ranjithlal, 2019; Kumar, 2011) and concentrates on the output dimensions of performance (Limberg, 2008). In the context of the Indian HIV counselling programme, the existing measurements of effectiveness relate to the achievement of desired numerical outcomes (NACO, 2014). The cost-effectiveness of such programmes has been a crucial characteristic considered in evaluating quality (Freeman, 1999). Cost-effectiveness is defined as the identification of investments that contribute the most to better health, a crucial aspect for public health spending (Neumann et al., 2016).

Programme outcomes are typically set by stakeholder institutional decision-makers informed by management-based principles and practices that include population monitoring and stratification, developing and measuring programme outcomes, and evidence-based health care (Bialek, Beitsch and Moran, 2017). It supports effectiveness by weighing risks, benefits, and costs of a programme for the service users (Schoon et al., 2018). Such practice is mainly concerned with measuring physical inputs and achieving desired outcomes based on the outputs (Smith and Clark, 2006). The stakeholders who shape HIV programme effectiveness decisions are the donors like UNAIDS, (NACO, 2017a) and the Indian government who implement the programme as a federally funded central sector health scheme for prevention and control of HIV/AIDS (NACO, 2018b).

The measures of effectiveness for a HIV counselling programme (NACO, 2014) include a range of quantitative variables focusing on measurable outputs as the agents of improving quality, and follow the typical principles of PHPs around the world (UNAIDS, 2014). Standard principles of PHP effectiveness have been criticised for often ignoring historical social, cultural, and political issues (NACO, 2014; Lang, 2005; De Maeseneer, 2007). Crucially, PHP effectiveness is also criticised for its emphasis on institution driven criteria of effectiveness rather than programme effectiveness criteria identified by users and frontline health care workers (Hunter, 2016)

The lack of evidence on programme effectiveness and barriers in Una, from the perspectives of users, has resulted in gaps in its implementation. The existing evidence misses out the social research-based programme evaluation process. This process makes sure that every social action aims to improve users' conditions in an effective manner. This programme effectiveness is achieved by appreciating the users' perspectives and by adapting its organisational behaviour to the sociocultural and political environment of the locality (Rossi, Lipsey and Henryal, 2004). In the context of Una, the social realities of HRG clients and their challenges in accessing services are entrenched within the culture and religious-based society. Therefore, although the norm for evaluating effectiveness of the programme follows a technical, managerial, and top-down approach, it misses out the challenges of implementation (NACO, 2020). I followed a more critical way of looking at effectiveness as described in this section.

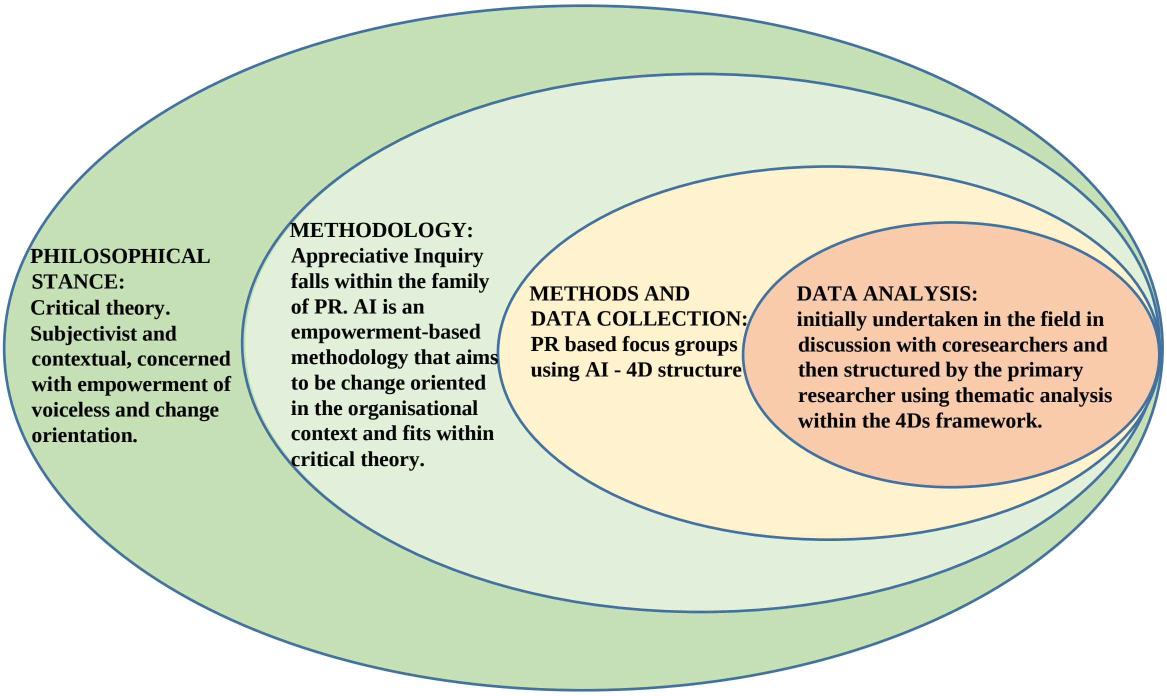
This study utilised a participatory methodology, specifically AI, guided primarily by the perspective of the strengths-based leadership philosophy of Peter Drucker. AI is commonly employed in organisational as well as systems research (Stavros, Stavros and Torres, 2018). AI emerged in the 1980s from the works of David Cooperrider and Suresh Srivastava in the United States (Simons and Havert, 2012). Since then, it has evolved as "the catalyst for positive change" (Cooperrider, Stavros and Whitney, 2008, p. 17) based on the principle that an organisation can only reach a positive future through collective involvement and methods that affirm, compel, and accelerate anticipatory learning. Here, AI presents reality as historical and dynamic, having been shaped by a range of social determinants and acknowledging different realities, especially the realities of the marginalised and voiceless, thus entrenching it within the critical theory paradigm (Ludema and Fry, 2008).

Ludema and Fry (2008) stated that AI methodology positions itself well within critical paradigms investigating sociocultural norms of marginalised populations as presented by these social realities, within the context of organisations (Grant and Humphries, 2006). The nature of religion-based alienation and isolation, its association to high-risk behaviours, and the resultant barriers to health care access faced by HRGs, is an under-researched subject. AI methodology facilitated investigation of these social contexts using a critical lens, while adopting a strengths-based approach towards the health system. It examines how these issues inhibit the effective delivery of the programme—an under-researched domain for both India and neighbouring nations (Idler, 2014; Marmot, 2008).

AI was considered an appropriate methodology to use in relation to the aim of this study because of its emphasis on empowering participants as research partners or CRs (Figure 1.2) from the inception of the study (Cooperrider and Whitney, 2005) and the agenda for change in organisational settings which is a specific characteristic of AI (Haski-Leventhal, 2015). It follows a participatory approach by engaging with the CRs, aiming to provide opportunities for voices. It also advocates for providing avenues for CRs to develop plans for improving services delivered to them through enabling them to express their perspectives about improving the programme. It also demonstrates appreciation for the CRs' local knowledge and allows them to contribute to designing an effective HIV counselling programme for Una district.

Figure 1.2.

Hierarchy of Research Design



Adapted from research onion (Saundersa, Lewis and Thornhill, 2012)

With its historical roots in the ideas of Lewin and Fal Borda's work on action research and Freire's education movement (Minkler and Wallerstein, 2011), the participatory research approach is focused on gaining knowledge through action and uses a "bottom-up" approach with a focus on locally defined priorities and perspectives (Cornwall and Jewkes, 1995). Emerging from its constructionist beliefs, AI allows the application of participatory techniques to unveil systems of power, marginalisation, inequities, and exploitation (Grant and Humphries, 2006; Ludema and Fry, 2008) that may affect the counselling experiences and outcomes of HRGs.

Given its focus on community voices, participatory research has been influential in international health systems research and community development projects (Oetzel et al., 2015; Almond, Cummings and Turner, 2015). The current research focussed on the socioeconomic context of HRGs, and operational aspects that inhibit effective delivery of the programme. A participatory approach enables the exploration of how these systems of differentiation are embedded in socioeconomically defined and enforced norms that have existed for much of India’s history. Finally, the approach creates a space for transformative arguments for practical implications and recommendations (Grant and Humphries, 2006).

In principle, AI aims to lead to social change through continuous action. This action involves thoughtful inquiry and understanding the life-giving forces that lead a system to peak performance. AI provides opportunities for a dialogue into these positive forces with an aim to nourish them as they are necessary to develop an effective system (Bushe and Pitman, 1991). Participatory research offers a well-suited methodological approach for AI, engaging the users in their own research and inquiring into the most life-giving forces in their system, the root causes of their success, and discovery of their positive core. Data collection and analysis are inseparable and are a collaborative exercise in this process (Mace et al., 2015). The data collection was structured into four phases of the AI process: Discovery – exploring the best of what is and what has worked in the past (Elliott, 1999); Dream – envisioning the best for their future (Carter, 2006); Design – planning and designing (Ludema and Fry, 2008); and Destiny – analysing the future of the design.

Understanding the experiences and challenges of HRGs and FCS in association with the programme took into account 1) the barriers to the HIV counselling programme for HRGs in India, at a local and national level; 2) the experiences of HRGs and FCS in relation to the programme; 3) approaches to addressing challenges faced by HRGs when accessing HIV counselling programme which involves collaboration between HRGs and FCS; and 4) the social factors affecting HRGs while accessing the programme. The findings of this study may have implications for transforming approaches to addressing the HIV counselling programme for HRGs in Una, India, and other contexts. The study contributes to the growing body of research that utilises AI as a methodology; and, more so, in examining the issues of people at risk of, or living with, HIV/AIDS.

1.5. Significance of the Study

The issue of the ineffectiveness of the HIV counselling programme has been severely neglected, especially for HRGs who have minimal voice in its development (Meehan et al., 2015; Manian, 2017). The study's specific attention to counselling related experiences, provides a significant opportunity in development of a targeted response to the counselling needs of HRGs of Una. Besides providing information on current trends in HIV counselling practices, the study presents a unique contribution to knowledge by creating a space for HRGs and FCS as CRs to improve the programme for Una. It also expands the existing body of research on using an empowerment-based methodology for improving the Indian HIV counselling programme. Finally, this study utilises a critical AI methodology for creating space for HRGs and FCS to share their perspectives to improve the HIV counselling programme.

1.6. Researcher Positionality

Given the nature of the study, the role as an external researcher interviewing HRGs and the FCS, and examining the cultural norms surrounding high-risk activities, it is useful to identify my personal and cultural assumptions going into the study. As an Indian researcher, I acknowledge India's recent growth in the global market, its ongoing economic reforms, its push for soft power on the world stage, and the limitations of its society and culture. With its rich culture, democracy, and international engagement, India's potential to be a soft power is highlighted more than other authoritarian and revisionist powers worldwide. Nonetheless, India is also known for social ills such as increasing incidences of drug use and a religion-based and caste-based value system that ostracises dating, prostitution, and same-sex relationships. These sociocultural and religious inhibitions and biases were instrumental in shaping the history of HIV/AIDS in India. It has been an illness that continues to impact the lives of the infected, their close ones, and the people around them.

After graduating in clinical sciences from Panjab University, Chandigarh, I first learned about HIV related research and prevention programme as a clinical data writer at a Clinical Research Organisation from 2006 until mid-2008. This company contracted clinical trials run by global pharmaceuticals and reported the adverse drug events in electronic case report forms. In 2008, I joined a Master's in Public Health at Punjab University, which triggered my professional concern on public health and epidemiology. During this course, I was involved with the National Health Mission (NHM) and the Chandigarh AIDS Control Society (CSACS) for HIV outreach activities in migrant communities. I undertook a survey-based project with IDUs for NHM, the results of which were presented at the National Seminar on Societal Aspects of Public Health organised by Panjab University Chandigarh.

The CSACS was also instrumental in organising the National AIDSCON 2011 conference, which introduced me to the national AIDS control programme (NACP). To expand ground-level understanding of the programme, I volunteered at an NGO that delivered HIV awareness activities to MSM, HTG, and FSWs in that area. During these activities, I recognised the critical role of peers in helping HRGs adopt safe practices and the similar role of PLHIV in helping themselves and those affected with HIV.

As noted above, I have been a public health researcher since July 2008, and all my research activities adopted quantitative techniques to target public health issues around Chandigarh. My education was focused on quantitative and numerical research outcomes. I was taught that qualitative methods are non-scientific and more critical for sociologists and management graduates.

After graduating in public health, I joined as a lecturer at my Alma Mater and trained HIV counsellors under the Saksham – a project funded by the Global Fund from 2010 until mid-2013. Since 2008, this project has supported the MoHFW in its fight against HIV by developing a better psychosocial support programme for HIV in India through counselling, capacity building, and community engagement (Gandhi and Rajan, 2013). It was here that I first learned that outcome evaluation for HIV counselling was a qualitative aspect and can never be evaluated at its totality using quantitative techniques. I learnt that these aspects dealt with the emotions of a HRG or a HIV-positive person, respecting factors like cultural sensitivity, respect, value, and confidentiality. The programme aimed to strengthen India's health system for the effective implementation of NACP. During my job tenure, I learnt that every PHP should have an explicit policy to strengthen local health systems and be embedded within the health system administration.

My interest in participatory research gained more focus during a workshop on 'Body mapping', a reflective process of creating life-size drawings representing people's identities within their social contexts (Skop, 2016). During this session, I learned that further to social aspects, other reasons also led to ineffective counselling services in North India. Common reasons included lack of infrastructure, delayed wages, and bureaucratic hurdles in delivering services. When asked about improving the effectiveness of counselling services, a group of HIV counsellors reached a consensus that an evaluation capturing the qualitative aspects of counselling was required. This perspective helped me narrow my research focus and ignited my interest in HIV counselling services. However, there remained questions regarding the absence of the voices of FCS, PLHIV, and HRG clients in informing programme delivery guidelines at the local level.

To further my understanding, I attended workshops on soft skills, effective communication, non-governmental services, and clients' privacy at Jamia Milia Islamia University, New Delhi. The topic took shape during one of these workshops when a co-participant asked, "Is the sole purpose of HIV counselling limited to increasing the HIV testing clientele and the number of distributed syringes and condoms? Have we lost its qualitative value?" To answer these questions, it became necessary to understand the experiences of HRGs, associated PLHIV, and FCS in the social, economic, and political context of the Indian society, particularly the HIV counselling service they were associated with.

During these workshops, I participated in discourses with members from HRG communities, some of whom were HIV positive. In these discussions, I gained insights into the deeply embedded attitudes of Indian society, discovering that risky behaviours, culture and religion, socioeconomic factors, and systemic roadblocks were the reasons that left people vulnerable to HIV infection. It also helped me understand the complexity of the disease related to cultural and religious beliefs, socioeconomic situations, and improper access to health services which collectively increase a person's vulnerability to HIV infection. I created networks during these workshops, which later laid the foundation for my fieldwork.

My colleagues and seniors appreciated the focus of my research as potentially helpful in gaining new knowledge for transforming the HIV counselling programme in India. It was recognised that the programme marginalised many HRGs and PLHIV; and stigma, discrimination, practising unprotected sex, and easy availability of addictive drugs continuously exposed the population to HIV and its associated social maladies. Stakeholder voices, if valued, can play an essential role in establishing best practices and better outcomes.

As a reflection of my interactions with HRGs and HIV counsellors, I presented a paper on stigma and discrimination associated with HIV/AIDS at the National Seminar on HIV/AIDS and Gender Concerns at Bhopal, India (2012). I also contributed to a paper regarding the legal aspects of HIV related discrimination, published in the *Indian Journal of Population Education* (Authors, 2012). During preparation for these papers, I learnt about the social norms that increased the vulnerability of HRGs to contract HIV, the reasons for stigma, and the legalities around such behaviours. Upon reflection, these experiences shaped the research topic and shifted my worldview about HIV from a communicable disease to a complex social problem.

With a teaching job and association with HIV counsellors, I gradually understood the importance of qualitative research in health. After attending training on qualitative research methods, I planned to research HIV counselling policy. Learning more about the subject at AUT University helped concretise the research position and understand the complexity of health policy research.

1.7. Thesis Structure

This thesis has been divided into eight chapters. The first chapter has provided an introduction and overview of the research. The aims and rationale, as well as the theory underpinning the study were outlined.

The second chapter presents an in-depth, contextual examination of the HIV epidemic in Una, Himachal Pradesh, and India. It provides a reference to the reported HIV prevalence and the social context in which HRGs were situated. It also reviews the data relating to the programme in the Indian context.

The third chapter critically reviews the Indian systems of health care and their applicability in HIV counselling, the donor influences on the programme, and the social determinants related to HRGs in India.

Chapter 4 presents the research design and discusses the methodological framework of AI which shapes the current study’s data collection and analysis processes. It also sets out the necessary ethical considerations, including the selection and recruitment of participants.

Chapter 5 and 6 presents the findings of the study in relation to the Discovery phase –the structural and social factors related to HRGs when they access the HIV counselling programme: and their impact on HRGs’ counselling decisions.

Chapter 7 discusses the shared vision of how the dream of an effective programme informed by the Dream, Design, and Destiny phases can achieved. The content depicts key moments of co-constructing dialogue for building the images of a shared future. During this process of co-construction, certain visions of the future for the programme were collectively generated. These included fostering a larger picture for HRGs’ vulnerabilities experienced in the processes of HIV counselling, and redefining their definitions for the programme; having greater clarity regarding the structural challenges in the programme and suggestions to tackle them; redefining the HIV counselling process and guidelines to addresses HRGs’ requirements; comprehensive data capturing and reporting methods for the programme utilising exponential technologies and digital health tools; and encouraging involvement of culturally valued Indian traditional healthcare methods in HIV counselling for improving lives of HRGs.

Finally, Chapter 8 presents the summary of analysis, the methodological limitations and implications, and the implications for HIV policy and practice in the context of district, state, and country. It includes structural and programme issues such as less dependency on state, moving away from verticality, lack of better resourcing; as well as issues relating to Indian public health more broadly such as need for newer direction for policy and practice. The need to relate the policy and practice with the social factors is discussed, more substantively in terms of the need to contextualise social determinants within the programme framework. Finally, recommendations and suggestions on best practice and methodological advancements and future research are offered with attempts to create a wellbeing model where these strategies have been incorportated for a sustainable public health system.

CHAPTER II – A SOCIAL EPIDEMIOLOGY OF THE HIV EPIDEMIC IN INDIA

> *It is not possible to control the overall HIV epidemic if it is out of control in India. Whatever success is recorded in India will immediately have an impact on the overall world situation just because of the sheer numbers.*
>
> Denis Brown, Country Coordinator, UNAIDS India
> (Steinbrook, 2007)

2.1. Introduction

This chapter presents a situation analysis, using a social epidemiology approach, of the HIV epidemic in India, the unique social context for HIV prevalence in HRGs of Una district, and the public health response with specific reference to the HIV counselling programme in India. The chapter starts by positioning the epidemic in Una in relation to the epidemiological patterns of its neighbouring regions and India as a whole. Following next is the specific focus on HRGs in Una and their social and economic contexts and behavioural profiles. The latter sections explore the effectiveness of the HIV counselling programme in Una and critique its position in a broader public health response to HIV in India.

Along with scholarly peer-reviewed publications, the epidemiological, social, and service utilisation data presented in this chapter are gathered from various HIV-related surveys conducted in India from 1985-2021 and the annual reports from the Indian HIV programme. The following is a brief on the sources that informed this chapter:

1. <u>Epidemiological data on HIV and estimates on service utilisation:</u> The epidemiological data presented in this chapter are gathered from the annual reports of the Indian National AIDS Control Programme (NACP). Since 2011, NACP has published its performance through annual reports on national HIV counts among different population groups, including the data on service delivery and outcomes

related to the HIV programme in India. The state-level programme effectiveness was reported in these reports through the number of PLHIVs, adult HIV prevalence, number of new infections, and annual AIDS-related deaths (NACO, 2017, 2021). NACP only targets the states with higher HIV prevalence. Hence the data of states where the prevalence is low, like Himachal Pradesh, is incomplete (Sgaier et al., 2012).

2. <u>HRG specific data:</u> In India, HIV sentinel surveillance (HSS) started as early as 1985; and in 1998, NACO formalised HSS to monitor the trends and patterns of the Indian HIV epidemic. Based on UNAIDS guidelines, the HIV prevalence of pregnant women attending ante-natal clinics was considered a proxy prevalence rate for measuring the rate of infection in the general population (NACO, 2015a). Until 2005, HSS data were limited to HRGs (FSWs, MSM, IDUs, and HTG) and pregnant women visiting ante-natal clinics in urban and rural areas. It did not capture adequate data on the migrant HIV epidemic (Sager et al., 2012). Only after 2005, HSS began to monitor bridge populations (SMMs, LTDs). From 1998 to 2015, there was a significant expansion in the number of surveillance sites (from 176 to 776). From 2007 to 2021, HSS also reported geography-based prevalence data on the HIV epidemic in India. Moreover, for HIV biomarkers, information on basic demographic parameters such as age, education, occupation, spouse’s occupation, and order of pregnancy were also collected. It was reportedly the most extensive HSS globally due to the population size monitored that measured the incidence of HIV in a country (NACO, 2015a).
3. <u>Social and economic contexts and behavioural profile of HRGs:</u> Integrated Biological and Behavioural Assessment (IBBA) 2014-15 was a behavioural survey conducted with an overall sample size of 1,380,400 HRGs across 31 Indian states. It was directed as a part of NACP phase IV to generate evidence on social context and

risk behaviours among HRGs in districts with high outmigration. IBBA aimed to support planning and prioritisation of programme efforts at the district, state, and national levels based on the survey report on social determinants affecting the high-risk behaviours (NACO, 2017b). IBBA reported the average number of HIV cases from four high priority districts of Himachal Pradesh, Una being one of them.

4. Population data: The population data for Himachal Pradesh and Una were gathered from the Census (2011, 2019), while the Open Government Data (OGD) platform was used to source the data on health care facilities (NHM, 2018). Some epidemiological data on HIV in Una was taken from OGD district level Health Management Information System (HMIS) surveys (NHM, 2019). For the latest population estimates of India, World Bank (2020) population estimates were also used.

The HIV epidemiological data presented in this chapter were collated from the latest reports on surveillance activities, surveys, and performance reports of the programme delivered in India and its state of Himachal Pradesh starting from 1990. There were limited historical data on the impact of HIV preceding this period. Though HSS provided an organised picture of the HIV epidemic in India, programme effectiveness and service usage patterns, none of these reports collected qualitative data regarding the same. The data have been sourced from the latest reports as much as possible. Table 2.1 shows two estimates from the NACP annual reports which have been cited in the below discussion on HIV epidemiology in Indian states. The recent estimates published in 2018 and 2021 are compared to the year 2015 when the field work for this thesis was conducted. The table shows 36 administrative divisions of India referred to as ‘states’.

Table 2.1

HIV Estimates Between 2015 and 2020 (NACO, 2015a, 2018, 2020)

States	**HIV Prevalence**			**PLHIV counts**			**New HIV cases**			**AIDS deaths**		
	2015	**2017**	**2020**	**2015**	**2017**	**2020**	**2015**	**2017**	**2020**	**2015**	**2017**	**2020**
Andhra Pradesh	0.66	0.63	0.66	394,661	269,973	302,710	7,524	6,545	2,260	9,249	8,460	7,070
Andaman Nicobar	0.07	0.14	0.13	186	446	480	11	63	20	18	15	20
Arunachal Pradesh	0.07	0.06	0.07	606	588	710	42	76	80	32	19	10
Assam	0.06	0.06	0.08	12,090	13,539	21,240	928	1,387	1,160	229	266	380
Bihar	0.25	0.16	0.17	150,689	115,448	128,800	8,234	8,854	5,590	7,514	3,304	1,770
Chandigarh	0.35	0.20	0.17	2,933	2,093	2,210	298	241	80	87	53	100
Chhattisgarh	0.19	0.13	0.20	30,838	26,206	42,850	1,984	1,547	2,610	1,062	870	990
Dadar Nagar Haveli**	0.18	0.17	0.18	463	519	1,200	69	57	70	19	9	10
Daman and Diu**	0.14	0.17	-	284	424	-	43	38	-	12	8	-
Delhi	0.23	0.30	0.38	30,216	45,726	66,810	1,591	3,097	2,900	331	575	690
Goa	0.40	0.42	0.25	4,619	5,944	4,360	94	208	40	122	307	110
Gujarat	0.42	0.19	0.19	166,333	91,766	103,890	10,589	4,518	1,890	6,067	2,123	510
Haryana	0.13	0.18	0.21	22,596	36,286	44,650	1,236	2,482	2,270	364	1,313	950
Himachal Pradesh	0.12	0.05	0.11	5,723	3,148	6,970	207	91	120	124	26	30
Jammu and Kashmir*	0.03	0.03	0.06	2,777	2,954	5,720	82	213	170	39	32	80
Jharkhand	0.17	0.14	0.08	34,386	33,367	22,440	1,910	2,596	960	1,355	1,330	280
Karnataka	0.45	0.47	0.45	199,060	247,413	255,150	2,383	5,008	1,220	3,744	8,450	4,050
Kerala	0.11	0.08	0.08	23,376	22,755	24,870	581	877	770	1,030	750	250
Madhya Pradesh	0.09	0.09	0.10	44,409	51,223	60,080	2,060	2,385	2,740	1,799	1,853	1,010
Maharashtra	0.37	0.33	0.35	301,453	329,744	390,300	3,574	5,951	7,820	6,766	10,104	4,370
Manipur	1.15	1.43	1.15	24,457	31,549	28,380	429	1,612	950	1,146	1,621	810
Meghalaya	0.06	0.11	0.53	1,122	2,141	11,160	45	191	680	14	23	280
Mizoram	0.80	2.04	2.37	5,762	16,773	20,730	230	1,503	1,100	79	474	170
Nagaland	0.78	1.15	1.44	11,050	17,029	22,770	513	1,232	1,450	287	537	310
Odisha	0.25	0.13	0.14	67,654	41,357	49,310	3,001	2,422	2,130	3,965	1,389	1,220
Puducherry	0.15	0.15	0.30	1,560	1,821	4,340	30	173	190	32	17	240
Punjab	0.19	0.18	0.27	36,794	40,632	65,080	2,059	1,898	1,350	523	757	430
Rajasthan	0.23	0.10	0.11	103,148	54,682	62,100	5,054	2,747	1,740	4,105	899	280
Sikkim	0.23	0.05	0.07	939	230	370	134	17	20	27	2	2
Tamil Nadu	0.28	0.22	0.23	142,982	141,895	157,740	4,007	3,632	2,420	3,763	2,801	1,150
Telangana***	-	0.70	0.48	-	203,723	158,420	-	9,324	2,560	-	10,157	1,520
Tripura	0.31	0.09	0.10	7,238	2,678	3,040	929	206	400	266	65	10
Uttarakhand	0.11	0.11	0.12	7,059	8,021	10,570	346	731	370	120	213	230
Uttar Pradesh	0.12	0.09	0.10	150,361	134,020	160,640	9,474	7,055	5,630	5,195	3,819	2,000
West Bengal	0.21	0.20	010	128,754	143,904	77,670	6,257	8,605	3,800	8,127	6,472	620
All India	**0.26**	**0.22**	**0.22**	**2,116,578**	**2,140,000**	**2,317,760**	**75,948**	**87,580**	**57,560**	**67,612**	**69,110**	**31,952**

* 2020 data for Jammu and Kashmir includes Ladakh.
** 2020 data for Dadar and Nagar Haveli include Daman and Diu.
*** Combined numbers of Andhra Pradesh and Telangana for 2015.
****No data for Lakshadweep and Ladakh for 2015.

2.2. HIV Epidemiology of India

The South Asian subcontinent, India, being home to an estimated population of 1.41 billion, is the second-most populous country and the largest democracy in the world (World Bank, 2023). The first HIV positive case in India was identified in 1986 among Chennai based sex workers with a history of unprotected sex with foreign tourists (Simoes et al., 1987). In 2020, an estimated 2.3 million people were living with HIV in India, making it the third highest in the world, after South Africa and Mozambique (Central Intelligence Agency, 2021).

As indicated earlier, the different administrative divisions of India are referred to as ‘states’. These states are further subdivided into districts. For exploring the HIV epidemiology of these states, the following sections compare the PLHIV counts, prevalence, incidence, and AIDS-related deaths depicting the effectiveness of the programme in selected states. For the state-based performance comparison, the last two estimates from 2015 and 2021 reported in the recent annual reports by NACP were compared to see the changes in epidemic patterns (NACO, 2018b, 2021). The state-based aggregates have been the most common medium of reporting HIV counts and other healthcare and demographic information for the Indian districts. For Una, state-level estimates for Himachal Pradesh were used to contextualise the HIV epidemiology of the district.

The HIV prevalence of a state is calculated based on average seropositivity among ante-natal clients who visit testing centres in various districts of the state. The HIV prevalence in India has continued to decline from an estimated peak of 0.38% in 2001-03 to 0.34% in 2007, 0.28% in 2012, 0.26% in 2015, to 0.22% in 2020. In 2020, the national HIV prevalence was estimated to be 0.22% (0.17-0.29) amounting to 0.23% among males and 0.20% among females (NACO, 2018b, 2021).

In 2020, eight out of 36 Indian states reported more than 100,000 cases. These states were Maharashtra, Andhra Pradesh, Karnataka, Uttar Pradesh, Telangana, Tamil Nadu, Bihar, and Gujarat which together accounted for almost 75% of the total estimated PLHIV (Figure 2.1). Maharashtra had the highest number of PLHIVs (390,300) and was thus categorised as a high priority state by NACP which could indicate a programme performance issue that was not reported, leading to the need for further investigation (Figure 2.2). It was followed by Andhra Pradesh (302,710) and Karnataka (255,150) (NACO, 2021).

Figure 2.1.

HIV Prevalence (%) for Different States of India (NACO, 2021)

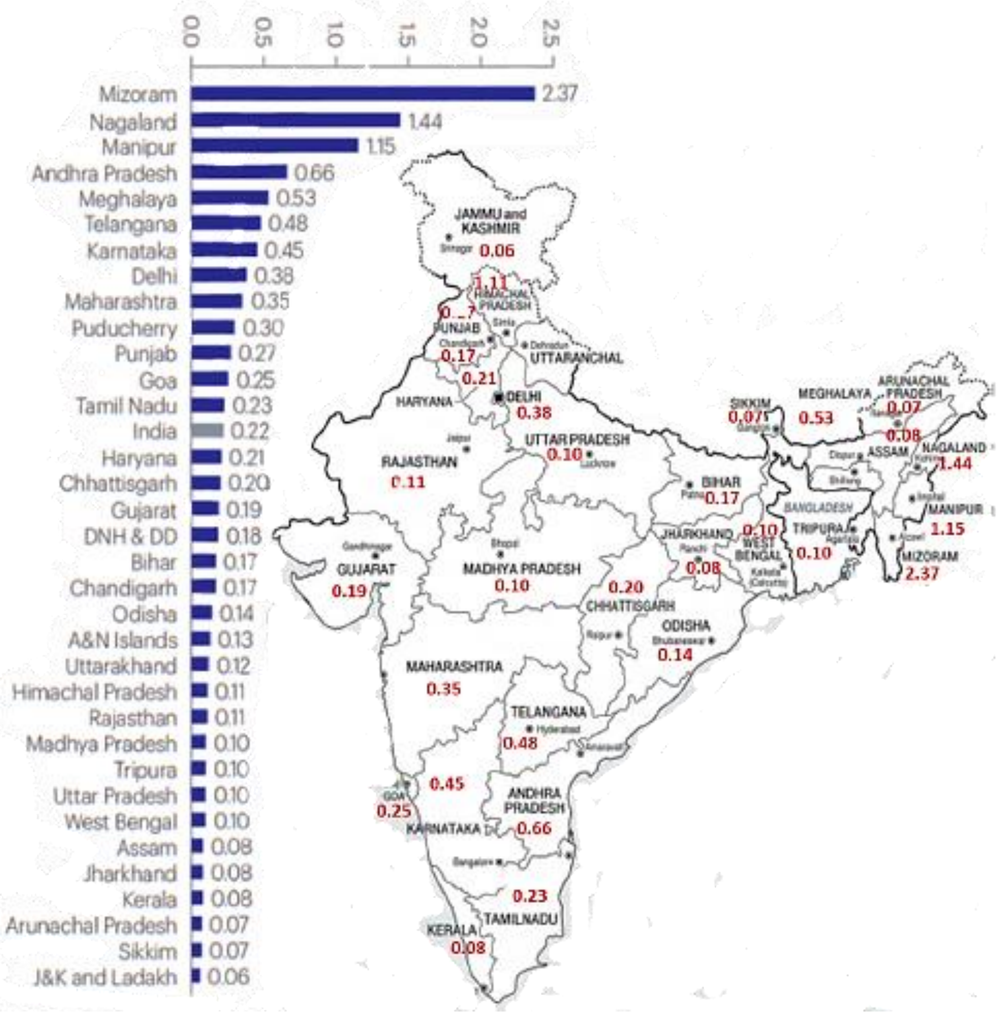
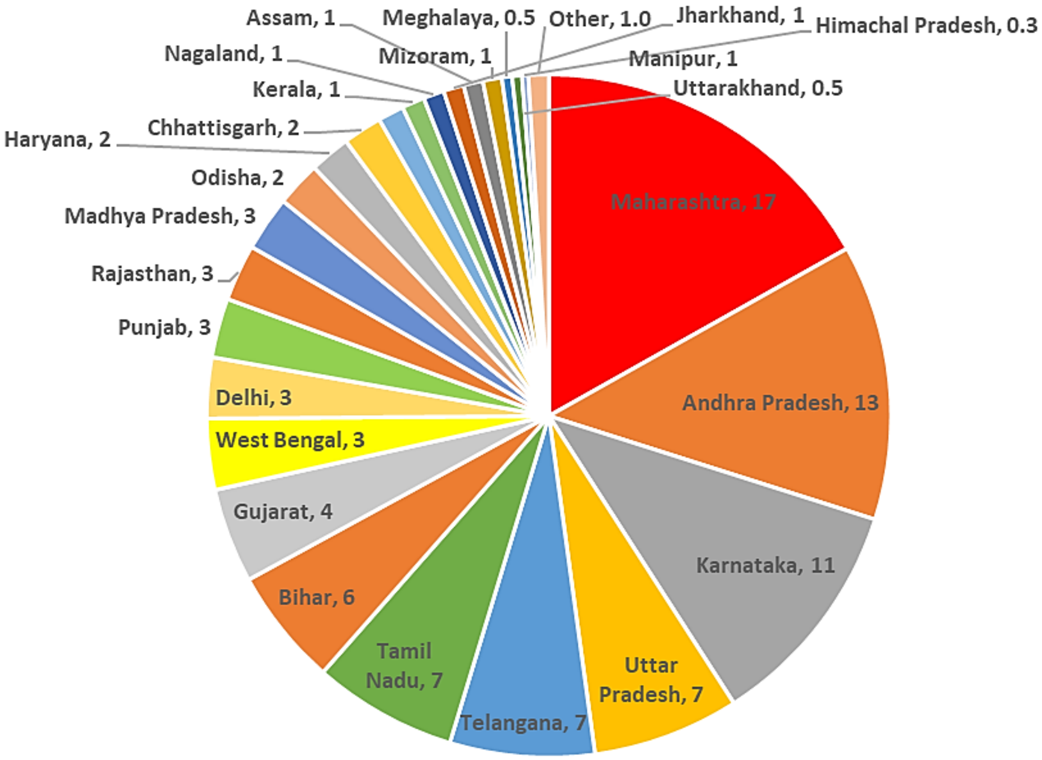


Figure 2.2.

States Wise Percent Distribution of Total PLHIV in 2021 (NACO, 2021)



In the same year, 22 states reported an increase in the number of PLHIVs compared to 2015, with a mean increase of 11%, while the national increase was only 9.5%. Apparently, this indicates three-fourth states had low programme effectiveness in terms of number of HIV positive cases (Tables 2.1 and 2.2).

The north-eastern state of Mizoram had the highest estimated adult HIV prevalence (2.37%) in 2021, followed by Nagaland (1.44%), Manipur (1.15%), Andhra Pradesh (0.66%), Meghalaya (0.53%), Telangana (0.48 %), Karnataka (0.45%), and Delhi (0.38%) (Figure 2.1). The highest increase in HIV prevalence, compared to other states, was seen in Mizoram in 2021 which was more than twice what was reported in 2015 (0.8%), along with a high AIDS related mortality in 2019, indicating inferior performance of the state AIDS control programme but still overlooking the factors that lead to the increase.

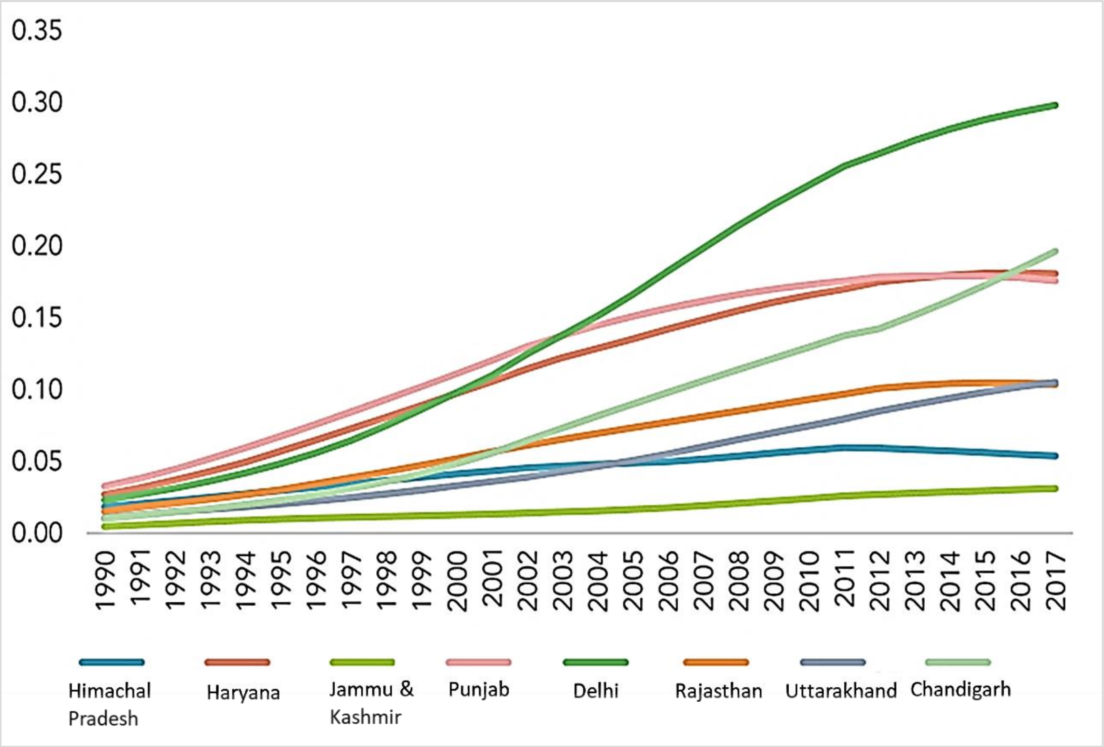
Although Gujarat showed a significant reduction in HIV prevalence and counts of PLHIV from 2015 to 2021, a 2018 press release reported that newer pockets of infections had emerged in the state (Sharma, 2018). Moreover, 13 states, including Delhi (0.38%) and Maharashtra (0.35%), reported HIV prevalence that was higher than the national average (0.22%). The prevalence of HIV in Tamil Nadu, a state with highest priority since the first HIV case for the country was identified, was 0.23%, which was lower than 2015 (Figure 2.2). All other states had lower levels of adult HIV prevalence than the national average and were considered low priority states by NACP (NACO, 2021).

Himachal Pradesh is a neighbouring state to the high priority states of Haryana, Jammu and Kashmir, Punjab, Uttar Pradesh, Delhi, Rajasthan, Uttarakhand, Chandigarh, and Bihar. Many residents of these states migrate to Himachal Pradesh for business and jobs. Exploring their trends was vital to understand the HIV epidemic in Una. Based on state figures of HIV from 2007 through 2017, these north Indian states showed an alarming upward trend in HIV prevalence (NACO, 2015c, 2017) which included the closest neighbours of Himachal, namely Punjab, Uttarakhand, and Haryana (see Figure 2.3).

Although not shown in Figure 2.3, this trend remained constant until 2021 (NACO, 2022) which could be indicative of a relative yet continued ineffectiveness of the state programmes or a higher reporting of cases due to expansion of the programme. To understand such granularity, a feedback mechanism that reports the social factors impacting programme performance could be helpful.

Figure 2.3.

HIV Prevalence in Himachal Pradesh and Neighbouring States 1990 to 2017 (NACO, 2018b)



HIV incidence refers to the estimated number of people who newly acquire the HIV virus in a year. Since 2007, the estimated number of new HIV infections per annum has decreased across India, albeit not uniformly in all the states. Annual new HIV infections in the north-east states of Assam, Mizoram, and Meghalaya, and in the northern state of Uttarakhand, increased significantly in the last 7 years; while Nagaland, Manipur, Delhi, Chhattisgarh, and Jammu and Kashmir showed a slower decline in new infections during the same time (NACO, 2018b, 2021).

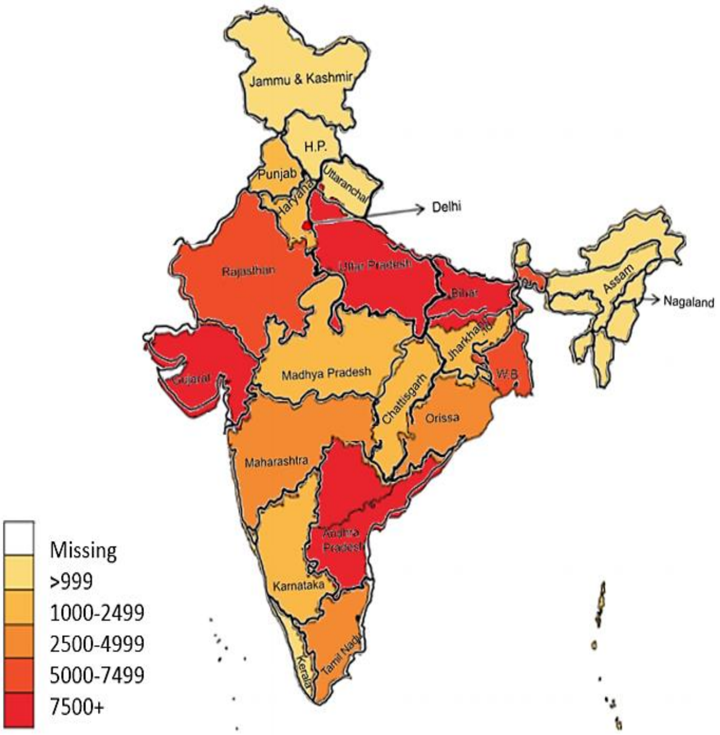
The estimated number of new HIV infections in India in 2015 (75,948) and 2017 (87,580) showed a 20% increase (NACO, 2018b, 2019). The reducing trend continued until 2021. In 2021, 11 out of 36 Indian states reported more than twice the increase in new infections compared to 2015 estimates (mean difference 1.8 times). Out of these

11, three states, namely Delhi, Haryana, and Jammu and Kashmir, are neighbours to Himachal Pradesh (NACO, 2018b, 2019). In the same year, more than 10,000 new cases were added to the existing number of PLHIVs in Bihar, Telangana, and West Bengal, amounting to one-third of the total new cases nationally.

There was an increase in new HIV infections in the northeast states of India too. The highest increase in new HIV cases was seen by Mizoram and Meghalaya, which was more than six times what was reported in 2015 (NACO, 2018b, 2019). In these years, many high priority districts were found in the low HIV burden states, focusing on newly emerging pockets of HIV infection in India, as indicated in Figure 2.4. Una is one such district that has a higher seropositivity but located in a low priority state of Himachal Pradesh (NACO, n.d.).

Figure 2.4.

State-wise Estimated New HIV Infections in 2015 (NACO, 2015c)

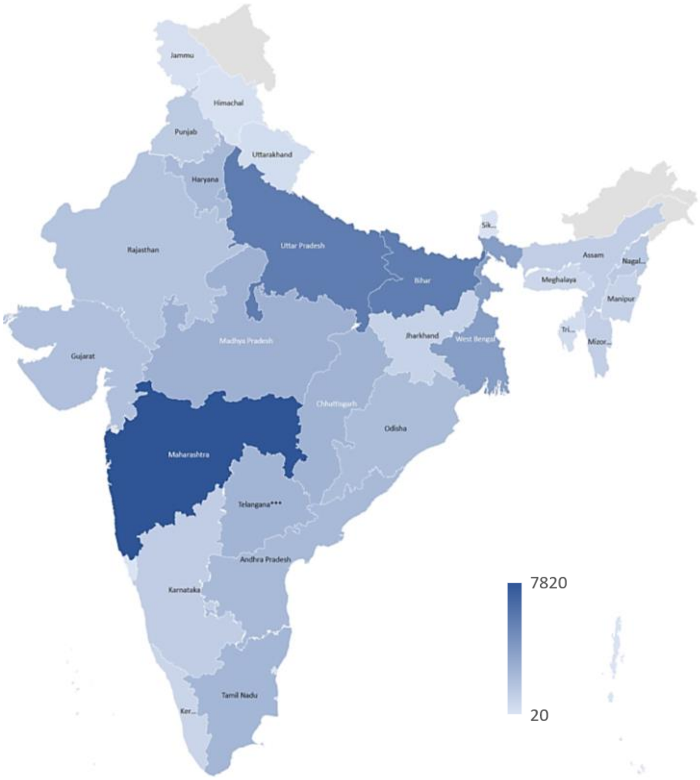


NB. Darker shade indicates higher counts.

New HIV infections were also higher in central, northern, and western Indian states, with several districts recording an increase. New Delhi, Haryana, Chhattisgarh, Madhya Pradesh, and Maharashtra accounted for 50% of these annual new HIV infections. The north-eastern states of Assam, Manipur, Meghalaya, Mizoram, and Nagaland also showed an increase in new infections (Figure 2.5) (NACO, 2018b, 2021). Nationally, women accounted for two-fifths of new HIV infections in both years in these states, which is why many states gave pregnant women a higher priority area followed by FSWs over IDUs, MSM, and HTGs.

Figure 2.5.

States-wise Percent Distribution of New HIV Infections in 2020 (NACO, 2021)

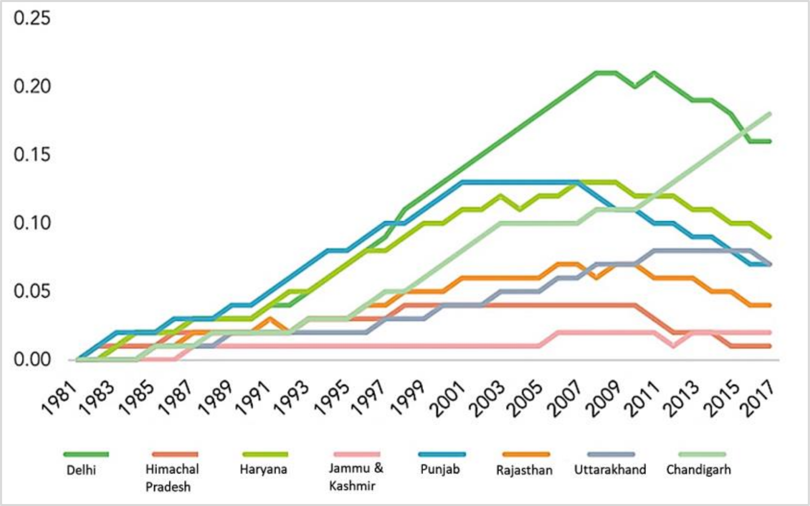


NB. Darker shade indicates higher counts while lighter shades show lower counts.

From 1981 to 2021, all northern states showed a stagnant to rising trend in adult HIV incidence. From the effectiveness point of view, this reflects expanded programme performance through surveillance sites that lead to higher reporting of cases, but misses the granularity at the level of social factors that may have played a role in this increase. HIV incidence in northern states was heterogenic both in terms of levels as well as in trends. In Delhi, Haryana, Himachal Pradesh, Punjab, and Rajasthan, incidence peaked (though at various times) and then started to decline. However, Delhi (as a part of Uttar Pradesh), Bihar, and Maharashtra had a much higher incidence level than the rest of the northern states (Figure 2.6).

Figure 2.6.

Incidence/1000 Uninfected Population in North States 1981-2017 (NACO, 2019)



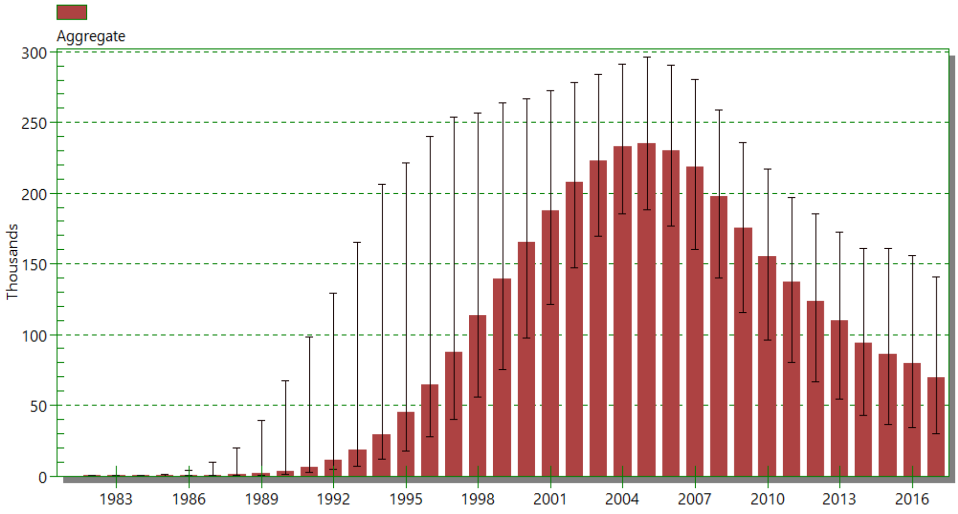
As mentioned earlier, the total PLHIV in India in 2015 were 2.11 million which was relatively lower than that reported in 2007 (2.26 million). This shows that 7 out of 100 PLHIV died with an overall HIV related mortality of 150,000. This gives an incomplete picture of the programme effectiveness and could indicate a failure of HIV treatment and care activities (NACO, 2018b). In 2017, nearly 3-decades after the beginning of the HIV programme in India, the AIDS-related deaths in India were the fourth largest in the world and highest among Asia and the Pacific countries (UNAIDS, 2018). In 2021 the numbers soared to 2.34 million (NACO, 2021); however, new cases and AIDS related deaths were lower compared to previous years.

The last 2 years saw lower PLHIV and related mortality counts mainly due to the public sector's devotion towards controlling COVID-19 and the restrictions on visits to the HIV testing centre. However, the interlinked vulnerabilities, disparities, and inequalities resulting from the collision of COVID-19 with a 40-year-old HIV pandemic that has claimed 37 million lives globally, remains unexplored (Edelman et al., 2020).

The number of AIDS-related deaths showed a declining trend since 2005 with 172,000 deaths in 2011, 142,000 in 2013, and 67,600 in 2015 (Figure 2.7) (NACO, 2012, 2013, 2015). However, AIDS-related deaths in 2017 were higher as compared to 2015. The death toll increased to 69,110 in 2017, the highest number of deaths being recorded in central and north Indian states, including the states neighbouring Himachal Pradesh (NACO, 2018, 2019), with some relaxation in numbers in 2021 (NACO, 2021).

Figure 2.7.

AIDS-Related Deaths in India Since 1983 (NACO, 2019)



While AIDS-related deaths dropped in other Indian states, northern states of Haryana and Delhi and north-eastern and central states of Assam, Bihar, Jharkhand, and

Uttarakhand (Table 2.1) showed increasing trends (NACO, 2018, 2021). These findings indicate that the focus of NACP was low in these states due to their lower HIV prevalence.

Despite sharing borders with neighbouring states reporting higher incidence and prevalence of HIV, Himachal Pradesh has remained in the bottom quadrant due to its low prevalence, incidence, PLHIV counts, or AIDS-related deaths (NACO, 2018, 2019). Further granularity on state and district level HIV data was obtained analysing the most recent figures from 2018 available for Himachal Pradesh (Himachal Pradesh State AIDS Control Society [HPSACS], 2018).

Compared to previous years, Himachal Pradesh reported a decline in HIV counts in 2018. The state experienced 91 new HIV infections and only 34 AIDS-related deaths showing a declining trend (NACO, 2018b). However, a media release in 2018 stated otherwise, challenging the credibility of the reported figures. It noted a significant increase in HIV incidence (313 new cases), total PLHIV counts (n=5,700), and AIDS-related deaths (n=5,700) in Himachal Pradesh (UNI, 2018).

Figure 2.8

HIV Seropositivity in Different Districts of Himachal Pradesh (Himachal Pradesh State AIDS Control Society [HPSACS], 2018)

It appeared that the figures reported by the government were not complete with a significant mismatch to what the press release stated. Although the reasons for the same are under-researched, it can be attributed to fewer surveillance sites in the state (NACO, 2018, 2019). Although there were no recent data available for Una, earlier reports state that Una has a high HIV seropositivity in comparison to other districts of Himachal Pradesh (Figure 2.8) (Hindustan Times, 2013; NACO, 2014).

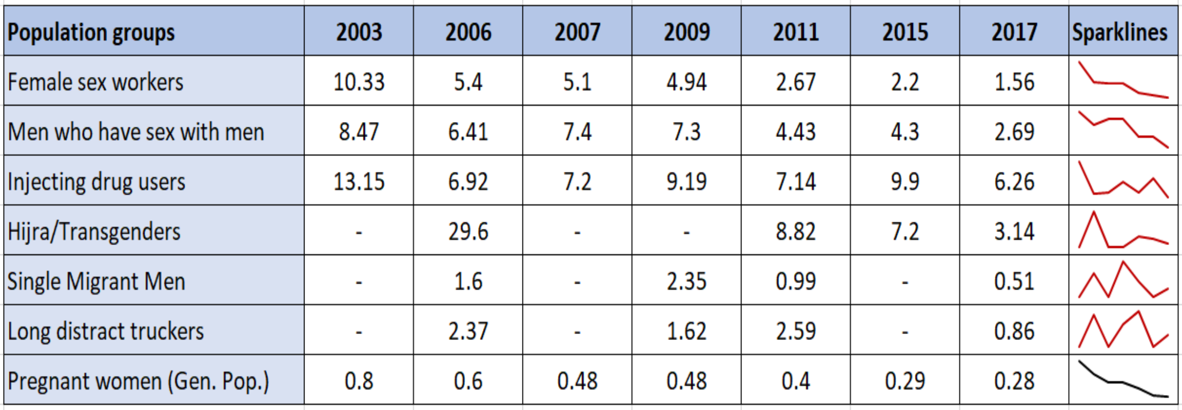
2.3. Social Context for High HIV Prevalence in HRGs in India and Una

UNAIDS (2003) recognised that globally certain groups were more likely to contract HIV and spread to the broader population. It reported that the reasons for a higher prevalence in these groups were unprotected sex (especially anal sex) with multiple or concurrent partners (or with a partner who has multiple or concurrent partners); and using unsafe needles and syringes for drug use (UNAIDS, 2003). In India, the epidemic was driven by unprotected paid sex with FSWs, unprotected anal sex between MSM and HTG people, and using the same needles for injecting drugs. HIV prevalence was consistently found higher in these groups throughout the years (Table 2.2); hence they are referred to as high-risk groups (HRG) (Ramachandran, 2012; UNAIDS, 2018).

Based on these transmission dynamics from 2017, India's HIV epidemic pattern was monitored among the population groups, mainly HRGs and bridge populations (NACO, 2017a). In 2017, the HIV prevalence among these groups is 6.26% for IDUs, 3.14% for HTGs, 2.69% for MSM, 1.56% for FSWs, 0.86% for LDTs, and 0.51% for SMMs (MoHFW, 2019). The adult HIV prevalence calculated from the prevalence in pregnant women increased from 0.22% in 2017 to 0.24 in 2019 (NACO, 2021).

Table 2.2

Comparing HIV Prevalence (%) by Population Groups (NACO, 2017b)



Population groups	2003	2006	2007	2009	2011	2015	2017	Sparklines
Female sex workers	10.33	5.4	5.1	4.94	2.67	2.2	1.56	
Men who have sex with men	8.47	6.41	7.4	7.3	4.43	4.3	2.69	
Injecting drug users	13.15	6.92	7.2	9.19	7.14	9.9	6.26	
Hijra/Transgenders	-	29.6	-	-	8.82	7.2	3.14	
Single Migrant Men	-	1.6	-	2.35	0.99	-	0.51	
Long distract truckers	-	2.37	-	1.62	2.59	-	0.86	
Pregnant women (Gen. Pop.)	0.8	0.6	0.48	0.48	0.4	0.29	0.28	

With lesser new infections, longer survival times, and a continuously growing population, the overall prevalence of HIV in India has not shown a notable change in the past decade. Nevertheless, the number of HIV infections among HRGs has been rising, which may not be the correct indicator for measuring programme effectiveness of states.

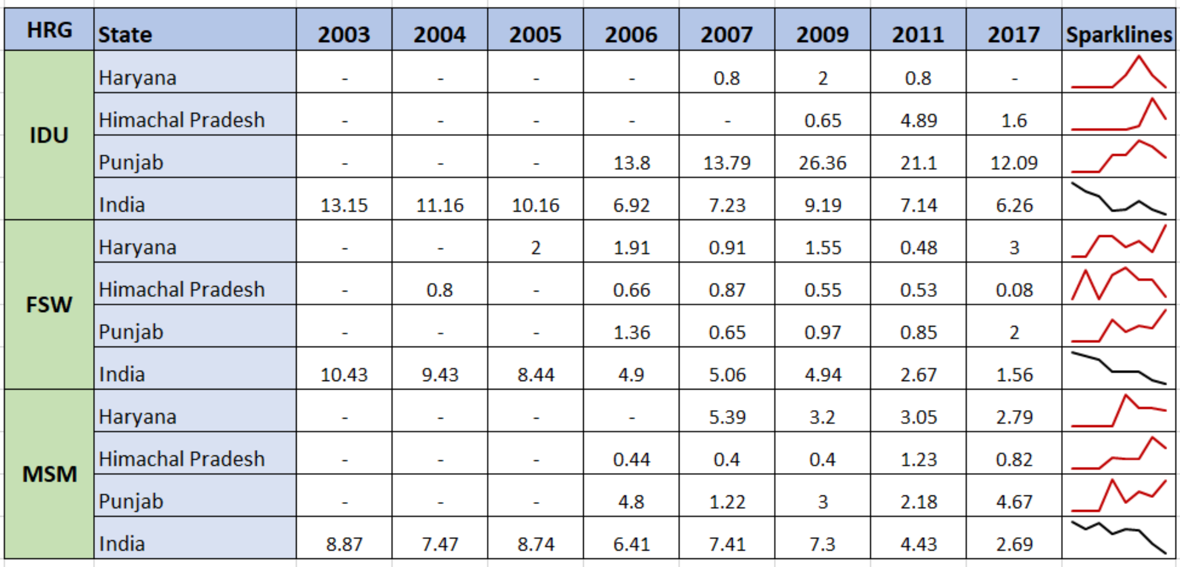
The Indian HRGs are often vulnerable in relation to sexual disease because of a range of social determinants (Rao, 2016). The HIV infection has implications for productivity and household income concerns (MoHFW, 2019); whereas social determinants create barriers to accessing services (Grove et al., 2021).

The IBBS 2014-2015 reported that HRGs were engaged in all high-risk activities in relation to HIV (NACO, 2015b). Despite the high prevalence amongst HRGs, their significant vulnerabilities, and the risk they offer to the general population, little attention has been given to understanding these social determinants.

Since 2007, the HIV prevalence among HRGs of North Indian states remained consistently higher than the general population. As there were no reports for state-level HIV prevalence among HRGs after 2017, the HIV prevalence trends shown here are based on data available from the previous years.

Table 2.3.

Comparing HIV Prevalence of Core-HRGs Among Adjacent States (NACO, 2017b)



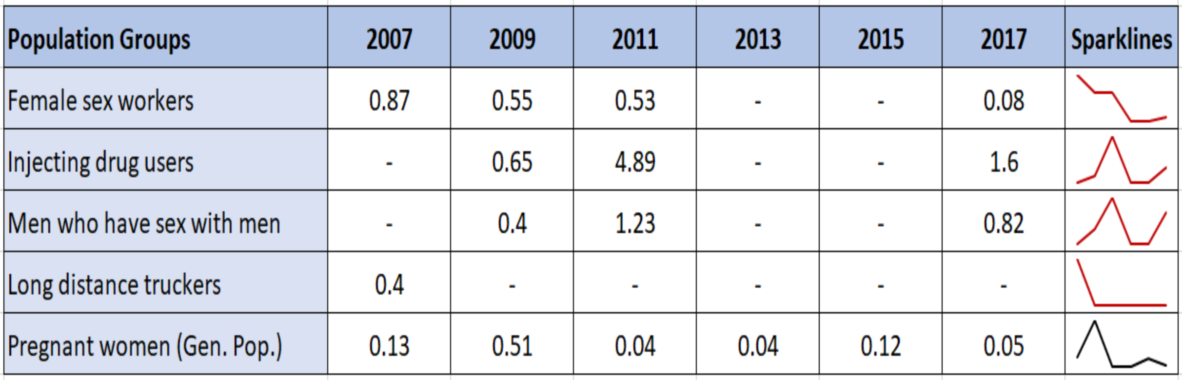
HRG	State	2003	2004	2005	2006	2007	2009	2011	2017	Sparklines
IDU	Haryana	-	-	-	-	0.8	2	0.8	-	
	Himachal Pradesh	-	-	-	-	-	0.65	4.89	1.6	
	Punjab	-	-	-	13.8	13.79	26.36	21.1	12.09	
	India	13.15	11.16	10.16	6.92	7.23	9.19	7.14	6.26	
FSW	Haryana	-	-	2	1.91	0.91	1.55	0.48	3	
	Himachal Pradesh	-	0.8	-	0.66	0.87	0.55	0.53	0.08	
	Punjab	-	-	-	1.36	0.65	0.97	0.85	2	
	India	10.43	9.43	8.44	4.9	5.06	4.94	2.67	1.56	
MSM	Haryana	-	-	-	-	5.39	3.2	3.05	2.79	
	Himachal Pradesh	-	-	-	0.44	0.4	0.4	1.23	0.82	
	Punjab	-	-	-	4.8	1.22	3	2.18	4.67	
	India	8.87	7.47	8.74	6.41	7.41	7.3	4.43	2.69	

For Himachal Pradesh, IDUs and MSM were the two HRGs that showed a higher prevalence of HIV in 2006 - 2017, while the prevalence in FSWs remained the lowest. Table 2.4. shows that IDUs maintained a high HIV prevalence with an average of 7.5% since 2006, followed by HTG, MSM, and FSWs. The bridge population groups, LDTs and SMMs, have shown a lower HIV prevalence. However, their prevalence had remained twice the HIV prevalence among pregnant women, indicative of ineffectiveness of targeted intervention in the state.

The national prevalence of HIV was the highest in IDUs, followed by MSM, while FSWs had the lowest (Table 2.4). The prevalence trends in Himachal Pradesh were similar to the neighbouring states (Table 2.4) (NACO, 2017b), where the prevalence of HIV in HRGs compared to the general population was high (NACO, 2015a, NACO, 2019). Unlike other states, Himachal Pradesh had no data on HIV prevalence among HTGs and SMMs. This lack of data could be attributed to fewer HIV surveillance activities in the state for these groups.

Table 2.4.

HIV Prevalence of Himachal Pradesh (NACO State Facts 2017)



Population Groups	2007	2009	2011	2013	2015	2017	Sparklines
Female sex workers	0.87	0.55	0.53	-	-	0.08	
Injecting drug users	-	0.65	4.89	-	-	1.6	
Men who have sex with men	-	0.4	1.23	-	-	0.82	
Long distance truckers	0.4	-	-	-	-	-	
Pregnant women (Gen. Pop.)	0.13	0.51	0.04	0.04	0.12	0.05	

2.3.1 Social Contexts of HRGs of Una

The section examines the social contexts of three prominent HRGs of Una—FSWs, MSM, IDUs—through the lens of education, age, employment, family, finances, urbanisation, and interstate HIV transmission dynamics. It also delivers a concise discussion on preventive practices followed by HRGs. The section includes some discussion on cultural aspects of high-risk practices and a critique on the inadequate representation of HRGs in the HIV epidemiology of India.

Although India is a signatory to numerous international agreements on the rights of women and has a constitution that prohibits discrimination and exploitation by gender, and a plethora of related legislation, it has failed to satisfactorily protect the human rights of women—particularly those of sex workers. This is manifested by violence in the sex industry, trafficking child sex workers, lack of access to health care, and higher levels of HIV infection. Policies that revolve around rescue and rehabilitation are based on the premise that sex work is immoral and are unlikely to effectively promote the well-being of sex workers (Misra et al., 2000).

Due to the nature of their occupations, FSWs face considerable discrimination that interferes with them accessing prevention services, acting as a barrier to the adoption of safer practices. The literacy rates of FSWs from Una are better than the national average, and they are aware of HIV prevention practices (NACO, 2015b). However, their challenges are unemployment, discrimination, domestic violence, and limited choices available for work. Left with sex work as the only option, they often practise at unsafe places like parks and roadsides in urban Una. Some of these FSWs are less than 18 years of age when they enter the sex business (NACO, 2015b).

In Una, 16% of FSWs experienced stigma in social settings, while 8% experienced stigma in hospital settings (NACO, 2015b). Some FSWs had also experienced physical violence from their customers or family members; yet, only one-fourth complained to someone about it (NACO, 2015b). Others reported less consistent use of condoms (60%) for sex work (NACO, 2015b) which could be due to male partners' unwillingness to wear a condom during the sexual act (Bowling et al., 2018) or due to the stigma associated with getting condoms from shops or NGOs.

Until very recently, homosexuality and sexual activities involving transgender were criminalised as sexual activities against the order of nature under Section 377 of the Indian Penal Code (British Broadcasting Coorporation, 2018; Gupta, 2006). MSM and HTG in India, therefore, experience multiple forms of social and legal discrimination (Chakrapani et al., 2002; Chakrapani, 2010). The social intolerance and cultural pressure for men to engage in heterosexual relations have consequently led many Indian MSM to marry women and have children (Dandona et al., 2005). This practice has been commonly observed in MSM residing in Una (NACO, 2015b).

MSM in Una are literate and know about preventive measures to protect themselves from HIV. However, social factors making them more vulnerable are the criminalisation of male-to-male sex, social discrimination, and physical violence (NACO, 2015b). MSM in Una face considerable discrimination, including physical and sexual harassment. It was reported that one-third of MSM in Una had experienced physical violence but, in contrast to FSWs, most of these cases were reported to someone (NACO, 2015b). However, MSM face more discrimination than FSW both in public spheres and at health facilities (NACO, 2015b).

As discussed earlier, many MSM hide their homosexuality from society by getting married and having children (NACO, 2015b). However, many MSM sex work for money and often avoid consistent use of condoms. Many reported condom breakages and used lubricants for the sexual act (NACO, 2015b), which might be due to the unavailability of anal condoms in Una (NACO, 2017b; Ramanathan et al., 2013). However, in contrast to FSWs, many MSM obtain free condoms from NGOs or buy them from shops (NACO, 2015b).

IDUs, by the very nature of their criminalised and illegal behaviours, are more likely to be stigmatised and come under the purview of law enforcement and curtailment of their human rights (Sarin et al., 2011). IDUs are also frequently denied the fundamental right to care, and only 10% of IDUs worldwide are reached by public health interventions (Beyer et al., 2010). Access to health services is often found to be impeded by stigma and discrimination (Ahern, Stuber and Galea, 2007; Ronzani et al., 2009; Wolitski et al., 2009).

In Una, IDUs were found to be literate and knew how to protect themselves from HIV infection (NACO, 2015b). Heroin was the most commonly used drug in Una, and nearby districts of Punjab, with the racket involving some police officials too (Bodh, 2018). Nearly a third reported taking the first dose of drugs when they were less than 18 years of age. A total of 50% IDUs injected drugs more than two times a day. Almost all of them preferred to inject in groups, of which 25% shared needles during the last injection they took (NACO, 2015b). Most IDUs obtain needles from NGOs or shops and use public parks for injecting narcotic drugs. Sixty percent of users throw used needles in ordinary dustbins or leave them at the injecting location (NACO, 2015b).

Compared to other HRGs, episodes of physical violence were more frequent with IDUs due to stealing money to buy drugs or drugs-related mental impairments that lead to fights with random people (NACO, 2015b). Half had sex with a male partner in exchange for money to buy drugs. IDUs also face significant levels of discrimination both in the public sphere and at health facilities (NACO, 2015b); hence, they rarely visit HIV prevention services. Their addictive behaviour, criminalisation of those addicted to drugs, unemployment due to addiction, social isolation, peer pressure, and involvement in drug sales and purchase were the key factors that made them vulnerable.

2.3.2 Proxy Prevalence and its Challenges

The HIV epidemic in India is characterised by having a high prevalence among HRGs, moderate prevalence among bridge populations, and low prevalence among the general population, which are used as measures of effectiveness of the Indian HIV programme (NACO, 2015c, 2017c). Although HIV prevalence in India did not show a notable change in the past decade, with many new infections and a continuously growing population, the overall HIV counts were rising. These data are sourced through surveillance activities conducted in various Indian states to monitor the trends and patterns of the Indian HIV epidemic. These surveillance activities gave more importance to the HIV rates among pregnant women but did not capture adequate data on HRG-specific trends (Sgaier et al., 2012). This section examines the prioritisation of districts based on proxy prevalence, which gives an inaccurate picture of programme effectiveness, the HIV epidemic and its transmission dynamics impacting a targeted delivery of counselling services to HRGs.

The HIV programme guidelines mandate that every hospitalised and non-hospitalised pregnant woman undergo HIV counselling and testing. These tests are kept voluntary for HRGs (NACO, 2007a). HIV prevalence among pregnant women is generally considered a more reliable indicator compared to the data on HRG clients. HIV seropositivity among HRGs is not included in the state or national average (NACO, 2015c, 2017); therefore, the prevalence among pregnant women is considered a proxy prevalence for the general population. This proxy prevalence is then used to measure the performance of programme and prioritising services at various administrative levels (Dee, 2017; UNAIDS, 2003).

However, the prioritisation of states based on proxy prevalence is not able to present an accurate picture of the HIV epidemic in that state as indicated by studies (Jha et al., 2010; Pandve and Giro, 2015), and which is the critical indicator for evaluating programme effectiveness. For instance, in Himachal Pradesh, it was observed that the seropositivity among pregnant women was significantly lower than those of general clients visiting testing centres (see Table 2.4.; Figures 2.9 and 2.10). The figures indicate that several HRGs might be getting tested under the category of general population, thus leading to an increased prevalence in the total population (HPSACS, 2018). The reports need to measure the HIV seropositivity of all the clients rather than only pregnant women getting tested for better evidence of programme effectiveness. Studies have argued that more accurate methods are required to measure the impact of the epidemic on the population (Jha et al., 2010; Pandve and Giro, 2015).

Moreover, the spread of infection in Una is characterised by higher rates of transmission among HRGs (as inferred in the previous section). However, as the proxy prevalence for Himachal Pradesh is low compared to other states, it remains a lower priority for the programme. Una district is also a low-priority district (NACO, 2015a, 2017c).

Figure 2.9.

Prevalence of HIV Among Pregnant Women Compared to the General Population (HPSACS, 2018)

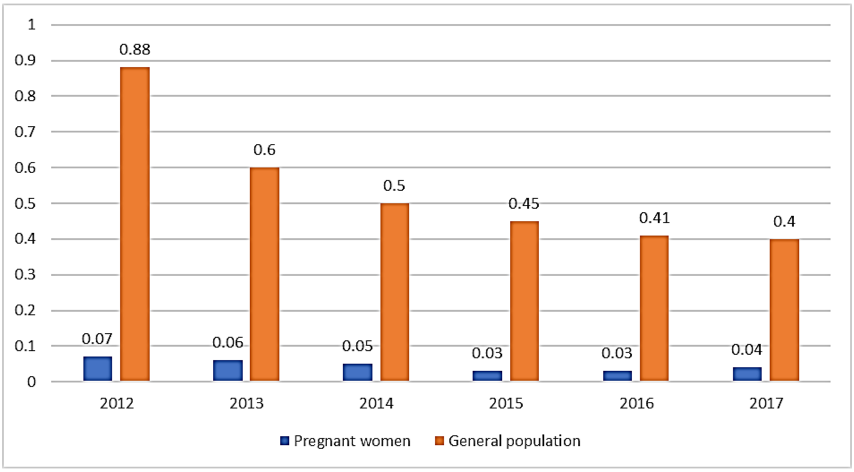
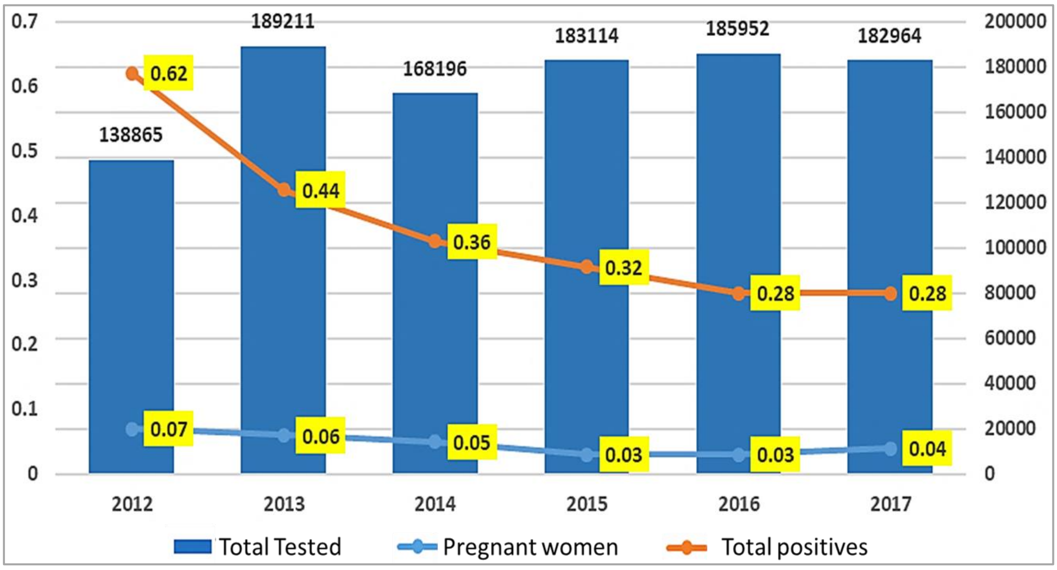


Figure 2.10.

Percentages of PLHIVs Among Pregnant Women Compared to the General Population (HPSACS, 2018)



In recent years, increased interstate migration has impacted the population diversity of HRGs in Una, which in turn has affected the HRG coverage. Unfortunately, Himachal Pradesh has failed to measure migration patterns and compute the number of HRGs, leading to an underestimation of these figures. This section argues that higher migration to Una from neighbouring states has led to an increase in HIV prevalence among HRGs. Their underrepresentation in service estimates had resulted in overburdening of the programme.

Una district, which forms a crucial industrial hub, is a densely populated district with a population of 521,173. In recent years, this ancient agricultural district has become an upcoming industrial hub for the automobile and steel sectors. Una connects with other industrial cities through road and railway links (see Figure 2.11), which plays a vital role in the growth of the industrial sector (Statistics Himachal, 2013). Due to its mineral resources and road networks with the other states, the district has experienced rapid industrialisation since 2012 (Press Trust of India, 2017).

Figure 2.11.

Map of Una District Showing Different Industrial Areas and the Soan River

Newer opportunities created by this rapid industrialisation has opened doors to workers from neighbouring states. As the facilities are limited, most migrant workers are single men who have left their families to work at the construction sites and brick kilns of Una district (Census, 2011). Moreover, SMM transport-related jobs attract

LDTs (NACO, 2019). SMM and LDTs working in low-paying, hazardous, and informal market jobs have poor occupational health and access to health services. Unable to afford private hospitals, they often return to their villages once they fall sick (e.g., contracting HIV). As severe implications, these men transmit HIV infections to their families living in their home villages. These two groups have been the core clientele of sex workers in India (Suryawanshi et al., 2013), with studies also indicating examples of high-risk behaviour in several other states (Rao et al., 2013).

Una district's high HIV seropositivity, compared to other districts, has been an indicator of increased high-risk activity (Figure 2.8) (Hindustan Times, 2013; NACO, 2014). In 2020, Himachal Pradesh had an HIV seropositivity 0.21 % by testing 2,20,873 clients out of which 473 were positive, an overall improvement in the seropositivity rates for the state compared to previous years making it a less priority state. However, Una district has always been high priority for the state in relation to HIV seropositivity, which had been reported to be 0.75% since 2001 (UNAIDS, 2004); whereas for Himachal Pradesh, the state HIV seropositivity was 0.53% (NACO, 2014) in those years. Similarly, in 2015, seropositivity for Una was 0.7% (Una Regional Hospital, 2015) which was higher than the state average of 0.53% (NACO, 2014). In 2017, among the 12 districts of Himachal Pradesh, Una had the highest HIV seropositivity (0.93%), followed by Kangra and Hamirpur (Figure 2.8) (HPSACS, 2018).

2.4. Public Health Response to HIV in India and Una

The NACP is India's public health response to HIV epidemic run under the NACO, a subsidiary under the Indian Ministry of Health. It is implemented entirely by the central government as a 100% centrally sectored scheme (NACO, 2016b) where the financial resources are not shifted to states (NITI Aayog, 2015).

Following the first few cases of HIV/AIDS were reported in 1986 (Jayaraman, 1986), the AIDS task force was commissioned (Ramachandran, 2012) that confirmed the epidemic was concentrated among HRGs (Ghosh, 2002). Subsequently, the first phase of NACP was launched in 1992 with a World Bank credit of USD 84 million aiming to implement a comprehensive programme for preventing and controlling HIV/AIDS in India and demonstrating the country's commitment to the UNAIDS (NACO, 2016b). This phase was implemented to reduce morbidity, mortality, and impact of AIDS and focused on awareness generation, setting up surveillance system for monitoring HIV epidemic, measures to ensure access to safe blood, and preventive services for high-risk group populations (NACO, 2016a).

By the 1990s, all Indian states had reported HIV/AIDS-infected cases (United Nations General Assembly Special Sessions [UNGASS], 2008), including Himachal Pradesh. As surveillance activities expanded, the number of infected people showed an increase. In response, the second phase of NACP was launched in November 1999 (NACO, 2016a), introducing HIV counselling and targeted interventions for HRGs (NACO, 2016a). This phase was launched with World Bank credit support of USD 191 million. Its HIV counselling component was as a part of strategic shift to reduce the spread of infection. Ever since, HIV counselling programme has been the gateway to refer HRGs, across Indian districts, to treatment and support services as needed (NACO, 2016a).

As a response to the increased surveillance in the initial phases, PLHIV increased from 3.7 to 5.1 million, a staggering increase of 40% in 6 years from 1999 to 2005 (Khan and Bano, 2008). The Indian government launched the third phase of NACP in July 2007 with the goal of reversing the epidemic and aimed to further strengthen the programme at the district level. Prevention and care, support and treatment, have been the key pillars for this programme with HIV counselling as a vital component (NACO, 2016a). The programme is currently in its fourth phase which was launched in 2012. It has a budget of USD 2 billion that includes 23% funds from the World Bank (NACO, 2016b). It aims for a phased integration of HIV services with the routine public sector health delivery systems and building capacities of governmental and non-governmental institutions and networks (NACO, 2016b).

2.4.1 HIV Counselling Programme as Part of the HIV Response

Launched with the NACP II, the HIV counselling programme for HRGs was designed to prevent the new HIV infection in high-risk communities or associated post-infection complications in the members of HRGs living with HIV (NACO, 2007b). Its activities aim to increase the reach of counselling and testing services to outreach areas, as well as to improve access to HRGs. It acts as the key entry point for HRG to access HIV diagnosis and treatment. The direct impact of providing these services is controlling new HIV infections within HRG groups while also controlling new infections in general (non-HRG) population. The general population has a higher chance of getting infected when involved in high-risk activities like transactional sex with members of HRGs or injecting drugs with IDUs (National Sample Survey Office, 2014).

HIV counselling was designed for people diagnosed positively to help them cope with the result and share information related to the disease (Figure 2.14). It helps clients to understand what the test results mean and to take informed consent before the test. If the test result is negative, clients are guided on protecting themselves from infections and provided information on the window period when the virus is undetectable and the importance of a retest. If the test turns out positive, clients were educated on ways to prevent infection transmission, the disease progression, and how to get connected with treatment and support options (NACO, 2007a).

2.4.2 FCS and Counselling Guidelines

In India, FCS have been at the forefront of caring for people infected with or affected by HIV. These are either employees of the district programme or an affiliated NGO associated with the programme. A wide range of professionals are employed as FCS including counsellors, lab staff, pharmacists, nurses, outreach workers, and peer educators. Some have trained to become HIV counsellors while others have learnt it during regular care and support activities. Some FCS are members of the HRG community employed for bringing more clients to the programme with the help of their community networks.

Trained counsellors have a degree in psychology, nursing, or social work. However, most FCS are not trained counsellors and have a basic competence in HIV counselling that helps them identify and manage patient problems. This experience makes them more confident in talking to patients about sensitive issues such as sexuality, death, and social stigma. They constantly interact with HRGs, giving prevention advice, clarifying treatment options, and keeping them safe in high-risk lives (Bor, Miller and Goldman, 2013). FCS follow HIV counselling and NGO operational guidelines for their counselling related activities (NACO, 2007a, 2007b).

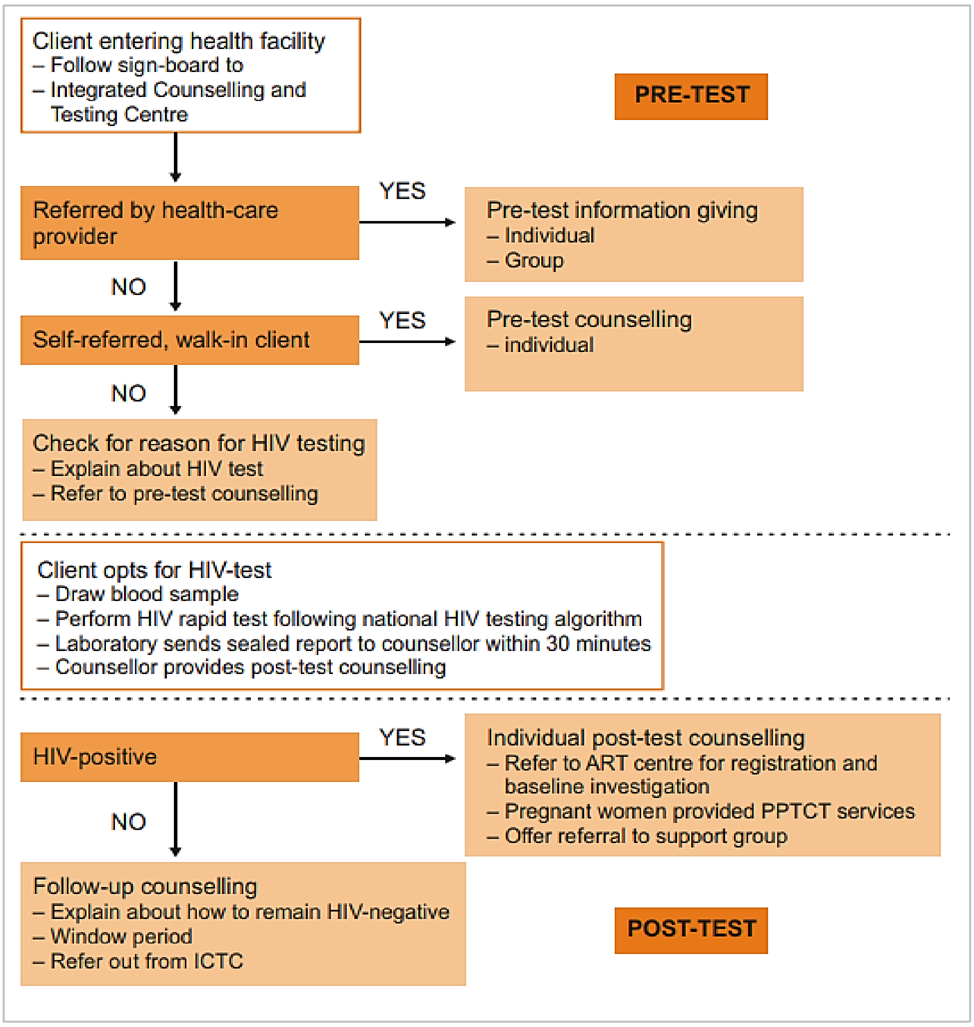
As per the guidelines, a pre-test counselling session takes approximately 20 minutes, usually at the district counselling centre where a trained counsellor addresses the gaps in the client’s knowledge around HIV prevention, risky behaviour, and gradually talks about the nature of rest and the consequences of a positive or negative result. The counsellor stresses that the client can still live a productive life for 10 or more years, and there are prospects for better therapy in the future and maybe cure. The counsellor discusses the client’s existing support system, like family and friends, and provides details about the window period and the need for a retest in a few months. The counsellor also conveys the need for a change in risky behaviour, information on taking an informed consent prior to the test, and schedules the next meeting for post-test counselling (Centers for Disease Control and Prevention [CDC], 2001; George, n.d.; NACO, 2007a; Oberzaucher and Baggaley, 2002).

Although the post-test counselling also takes around 20 minutes, it is usually shorter when the test result is negative. After receiving the test result, the client is asked to come back for a retest in 3-4 months for a confirmatory test and is asked to abstain from unprotected sex. If the result is positive, the client is given time to go through the phases of grief and come to terms with the situation. Once the client is calm, the counsellor educates the client of all possible help through medical care, psychological support, and referrals to treatment. The process takes approximately 30 minutes, dependent on the person’s response. Figure 2.12 shows the pre and post-test counselling process, similar to many other countries that strictly adhere to the UNAIDS guidelines for delivering HIV counselling (CDC, 2001; NACO, 2007a; UNAIDS, 1997). The guidelines advise giving sufficient time to clients to consider their results and help them cope with emotions arising from the diagnosis of HIV infection (NACO, 2007a, 2016). Untrained FCS follow specific operational guidelines for their activities at NGOs, de-addiction centres, and social service organisations targeted towards HRGs. These aim to improve their awareness, treatment adherence, nutrition, and enable behaviour change (NACO, 2007a). There are no separate counselling guidelines for untrained FCS.

NACP is the primary provider of HIV counselling and other HIV-related programmes and services to HRGs in India. Following the UNAIDS HIV prevention and control model, NACP adopted a two-pronged approach for service delivery in India: prevention; and care, support, and treatment (NACO, 2017c). Prevention services include counselling, testing, fresh needle-syringe supply for IDUs and opioid substitution, outreach services, prevention from other sexually transmitted diseases, blood transfusion, preventing parent to child transmission of HIV, condom distribution, awareness programmes, social mobilisation activities, workplace interventions, TV adverts, and behaviour change communication. The care, support, and treatment services include HIV confirmatory testing, free HIV treatment, early infant diagnosis for HIV, nutritional and psycho-social support, and referrals to tuberculosis testing and treatment (NACO, 2020).

Figure 2.12.

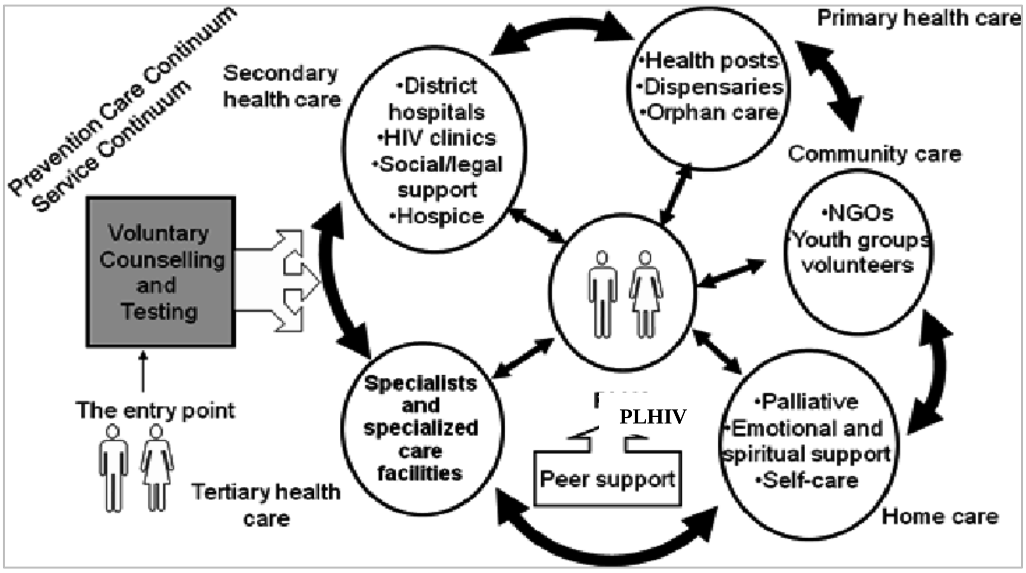
Client's Journey Through a Counselling Session and HIV Test (NACO, 2007a)



The HIV counselling programme is the entry point for HRGs to register with NACP. (NACO, 2020). It is the first critical step in detecting HIV in the community and linking clients to treatment. Its goals are to identify clients with high-risk behaviours, prevent them from contracting HIV and link the PLHIV to treatment services on time (Figure 2.13). It aims to provide quality support to clients either referred from healthcare settings or who have walked-in voluntarily to cope with a positive or a negative test result. HIV counselling provides the clients with HIV prevention information and allows counsellors to reinforce the importance of HIV prevention in clients on subsequent visits (Misra et al., 2016).

Figure 2.13.

Counselling Services Link Clients to Other HIV Related Services (Deb and Shukla, 2014)



The HIV counselling programme gets support from local NGOs who educate HRGs on HIV prevention and other sexually transmitted diseases. The counsellors at these NGOs refer HRGs for enrolment into NACP through the district HIV control unit. After enrolment at the NGO, HRGs can access condoms, sterile needles and syringes and opioid substitute therapy (OST). When needed, NGOs also refer HRGs to satellite services such as de-addiction, crisis response, social welfare schemes, and other services (NACO, 2016a).

2.4.3 Outcomes of the Indian HIV Counselling Programme

HIV counselling is an integral point connecting HRGs to HIV diagnosis and treatment. It was reported as vital in reducing the HIV burden amongst HRGs in developing countries (Brick, 2013; NACO, 2015d; Wariki et al., 2012). The World Bank, the key funder of HIV programmes in developing nations, reported that counselling leads to acceptance of HIV positive status by the individual. Without extensive population-based surveys, the data generated at counselling centres acts as an essential indicator of the prevalence of HIV infection, positioning it as a crucial part of the World Health Organisation's (WHO) guidelines for best practices in HIV prevention and control (WHO, 2005, 2007).

NACP offers HIV counselling services as a part of the HIV counselling and testing service (HCTS), earlier called voluntary counselling and testing (VCT). These services are delivered through integrated counselling and testing centres (ICTC) where clients are counselled and tested for HIV at their will or as advised by their medical practitioner. The service delivered at these centres include HIV prevention education, behaviour change communication, HIV testing, and linking clients to treatment services (NACO, 2020).

In the second phase of NACP, it was noted that HRGs hesitated to visit counselling centres due to concerns about disclosing their identity (Biradavolu et al., 2012). To address this challenge, the NACP II initiated NGO led programmes called targeted interventions (Gurnani, 2011; NACO, 2012). Targeted interventions attempt to create an enabling environment for HRGs to generate a positive attitude towards HIV prevention and treatment services under NACP (Bachani and Sogarwal, 2010). These intervention packages of prevention, support, and linkage services are provided to HRGs through drop-in-centres and outreach services run by NGOs under the jurisdiction of the district authorities. In these drop-in centres, HRGs interact with others belonging to their group who are already registered in the programme (NACO, 2012). A few registered HRGs support the NGOs as part-time peer-educators (NACO, 2007b). In this phase, the HIV programme focuses more on HRGs due to their dynamic patterns in HIV transmission by increasing NGO-led targeted interventions and opening more counselling and testing centres in high-priority districts for more geographical coverage of services (NACO, 2012).

By 2017, in NACP III and IV, there were 20,756 testing centres in India (NACO, 2017a)—five times the number in 2007 (NACO, 2007a). These centres were located at all levels of the public health system (NACO, 2007a) and operated as stand-alone buildings, mobile vans, offices within hospitals, and public-private partnership ventures (NACO, 2012). Their progress was reported through a computerised management information system (NACO, 2011).

2.4.4 HIV Counselling Programme in Una District

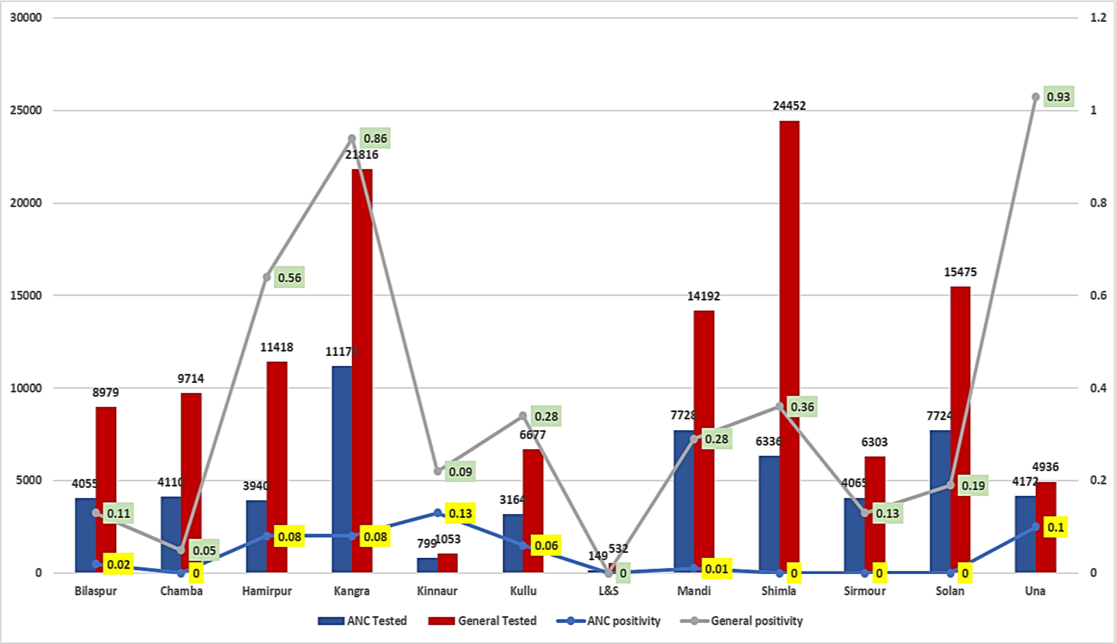
As there were no published data on the number of HRGs or HIV prevalence among HRGs in Una district, the HIV related data presented in the following section are based on personal communications with the district HIV programme officials in Una during the field work. In the absence of recent data, these remain Una's most recent figures (N.Sahore, personal communication, 25, February, 2015).

During 2013-14, 8,455 clients were counselled and tested for HIV in Una district, of which 59 were found to be HIV seropositive (Una Regional Hospital, 2015). In 2015-16, the number of clients tested further increased to 9,998, followed by 10,810 in 2016-17, showing a 10% increase in counselling and testing annually. However, the number of seropositive among HRGs remain consistently high in Una compared to other districts (Una Regional Hospital, 2015).

This high seropositivity could be associated with rapid industrialisation and increased migration to Himachal Pradesh from neighbouring states, primarily Uttar Pradesh, Bihar, and Punjab. NACP reported that HIV prevalence in MSM and IDUs has also increased significantly from 2007 to 2017 (NACO, 2017b), an increase that can be attributed to the inflow of truckers and migrant labourers (NACO, 2017b). Additionally, several media releases indicated illegal drug trade (Chaba, 2017; Bhargava, 2018), prostitution, and sex trafficking (Kumar, 2009) were high in the neighbouring state of Punjab that shares borders with Una leading to increased high-risk activities. The figures also indicate more HIV positive men in Una but, like any other Indian state, the higher numbers in men never get prominence when describing epidemic (Figure 2.14).

Figure 2.14

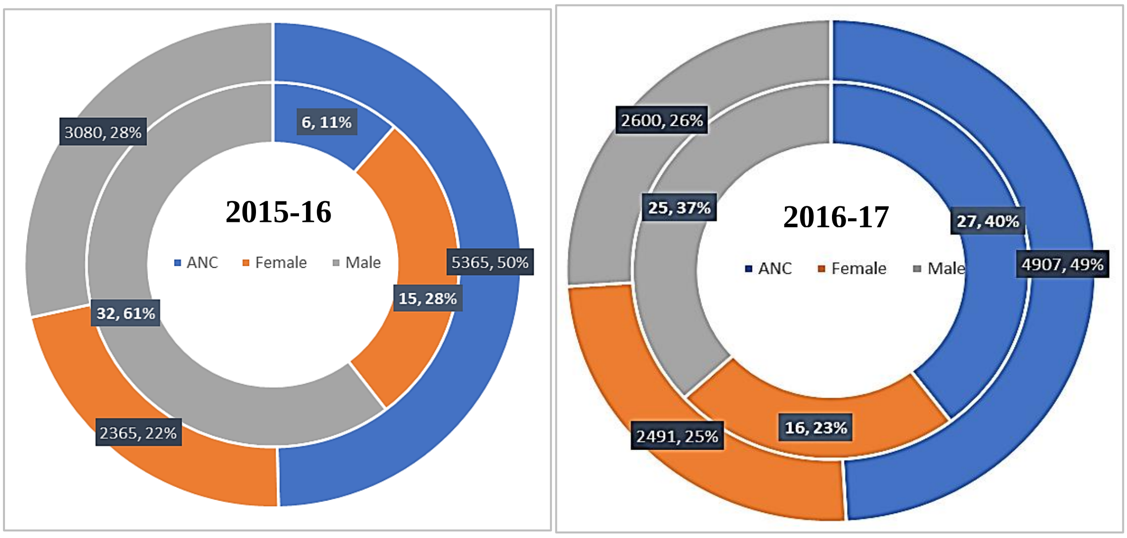
Comparing HIV Seropositivity of Pregnant Women and the General Population Tested at all Districts of Himachal Pradesh (HPSACS, 2018)



These reports denote that SMM, LDTs, and MSM are significant in the state's epidemic. The 2015 and 2017 HIV surveillance activities in Himachal Pradesh allotted most surveillance sites for pregnant women while none were allotted to these HRGs. Among the fewer percentage of men who visited testing centres, a high number were found positive. The data generated from two surveillance activities have been compared in doughnut charts denoting these discrepancies shown in Figure 2.15. The outer circles denote the number of people getting tested, while the inner circle shows the proportion of positive cases. In both years, women were tested more while men had a higher HIV positive test result. Interestingly, even after their higher positive results, men were targeted less in the 2016-17 surveillance activity compared to 2015-16 (HPSACS, 2018). Therefore, it can be concluded that the male HRGs of Una were less targeted by its programme.

Figure 2.15

Proportions of Positive Results for 2015-16 Compared to 2016-17 (HPSACS, 2018)

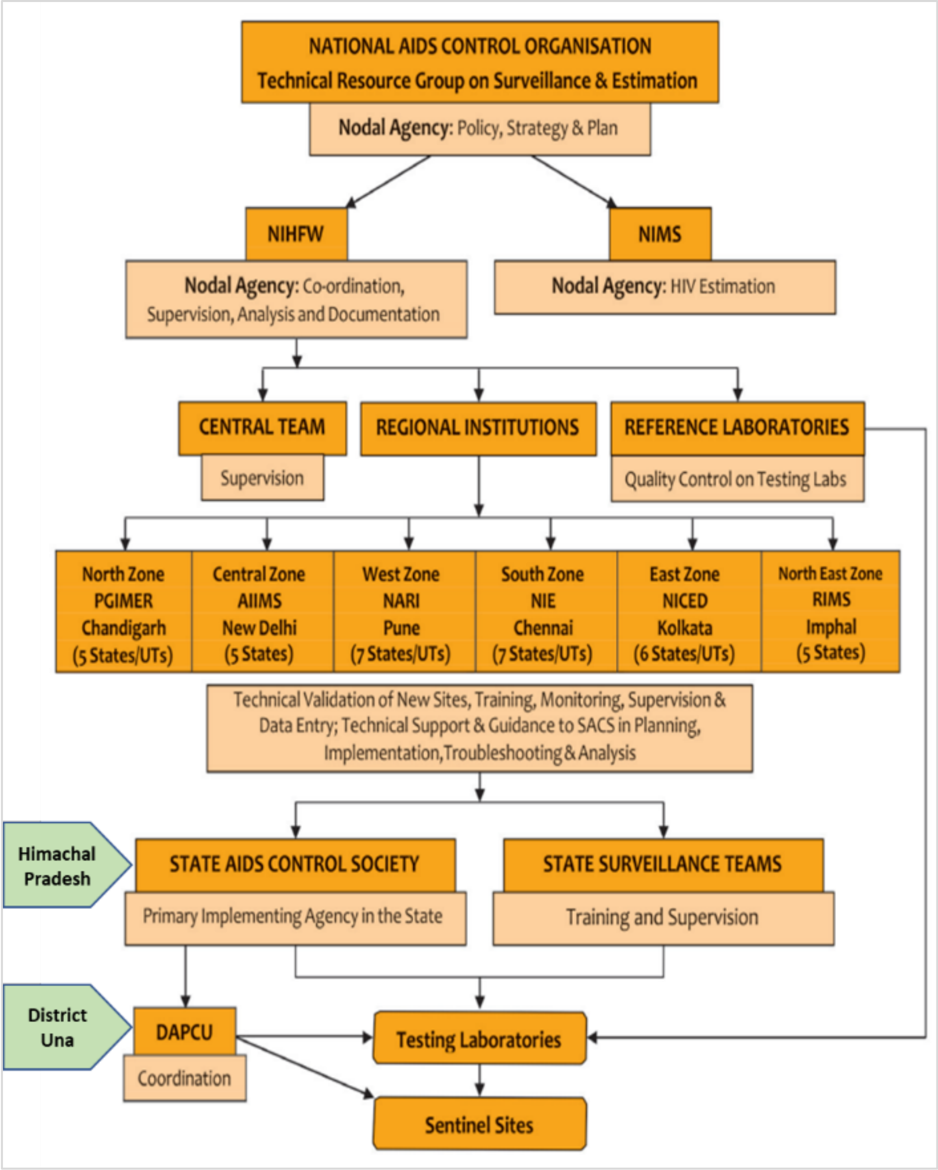


NB. Outer circle denotes the people tested while inner circle denotes positive test results.

Figure 2.16 shows the organisational structure for NACP positioning the Himachal Pradesh State AIDS Control Society (SACS) and the Una’s District AIDS Prevention and Control Unit (DAPCU) at the bottom of the pyramid (NACO, 2015a).

Figure. 2.16

Una District in the Implementation Structure of NACP (NACO, 2015a)



The organisational structure of Una district’s public health structure is divided into four units and several programmes. The Chief Medical Officer (CMO) is the district head for administration, operations, and financial management. Under the CMO’s supervision, the district medical officer manages four units (National Health Mission, 2013) and several programme managers. The other units include: Unit 1: clinical services, maternal and child health, family planning, food, and drug supplies;

Unit 2: immunisation, child sex ratio, adolescent health, HIV/AIDS, blood bank and addiction; Unit 3: leprosy, tuberculosis, malaria, disease surveillance and vector-borne disease; and Unit 4: non-communicable diseases, geriatrics, mental health, and tobacco control (N.Sahore, personal communication, 25, February, 2015). Where the federal authorities manage finances and broader operations, the state authorities provide technical support for service delivery and overall programme performance (NACO, 2020a).

HIV counselling infrastructure for Una district includes four counselling and testing centres each in Bangana (a hilly area); Daulatpur (plains at the hilly outskirts); the Una district headquarters at Civil Hospital; and a mobile counselling and testing centre. Most HIV tests were undertaken at Una testing centre in 2015. A few HRG-specific NGOs support these testing centres by referring HRGs to counselling and testing services. Clients who test positive are referred for free treatment to the nearest antiretroviral treatment centre at district Hamirpur (N.Sahore, personal communication, 25, February, 2015).

2.4.5 HIV Counselling Programme: An entry point for Targeted Interventions for HRGs

As discussed, the NGO led programmes, called targeted interventions for prevention, support, and linkage were implemented in the second phase of NACP towards HRGs (Gurnani, 2011; NACO, 2012). The HIV counselling programme acted as the key entry point to provide these services to HRGs registered in the programme (NACO, 2007a, 2016a). Focusing on HRGs' dynamic patterns in HIV transmission, more counselling and testing centres were opened in high-priority districts including Una for more geographical coverage of services (NACO, 2015c, n.d.).

This section reports its performance and shortcomings and further explains how a targeted intervention operates. Targeted intervention projects are intervention packages of prevention, support, and linkage services provided to HRGs under the district AIDS Prevention and Control Unit (DAPCU), which appoints specific NGOs for health promotion, education, and outreach. Many HIV prevention and control services are delivered to HRGs through these targeted interventions (NACO, 2014, 2018). Since NACP IV (2007-12), the HIV programme in India has significantly increased its attention towards the bridge population. In 2018-19, out of 11.5 million HRGs covered by NACP IV Extension (2012-17), 70% were members of the migrant population (Table 2.5). NACP implemented 1,443 targeted intervention projects in India to cover 1.25 million core-HRGs and 10.2 million bridge population. Therefore, the coverage for core-HRGs was 25% higher than in previous years. Likewise, for the bridge population, this coverage was more than twice of previous years (Figure 2.17).

The NACP reports of the years 2012-19 indicated that the targeted intervention coverage had been consistently increasing for all Indian states; the programme's coverage of HRGs increased by 2.3% in 2018-19 compared to 2017-18. As the NACP IV (2012-17) progressed, more attention was given to migrants and truckers, indicating that the programme coverage was utilised as a measure of effectiveness (NACO, 2019). Although the core group was kept as a high priority and NACP allocated more state-level targeted intervention projects to serve FSWs, IDUs, and MSM (Figure 2.17), it also increased the number of migrants covered by these projects (NACO 2012-19).

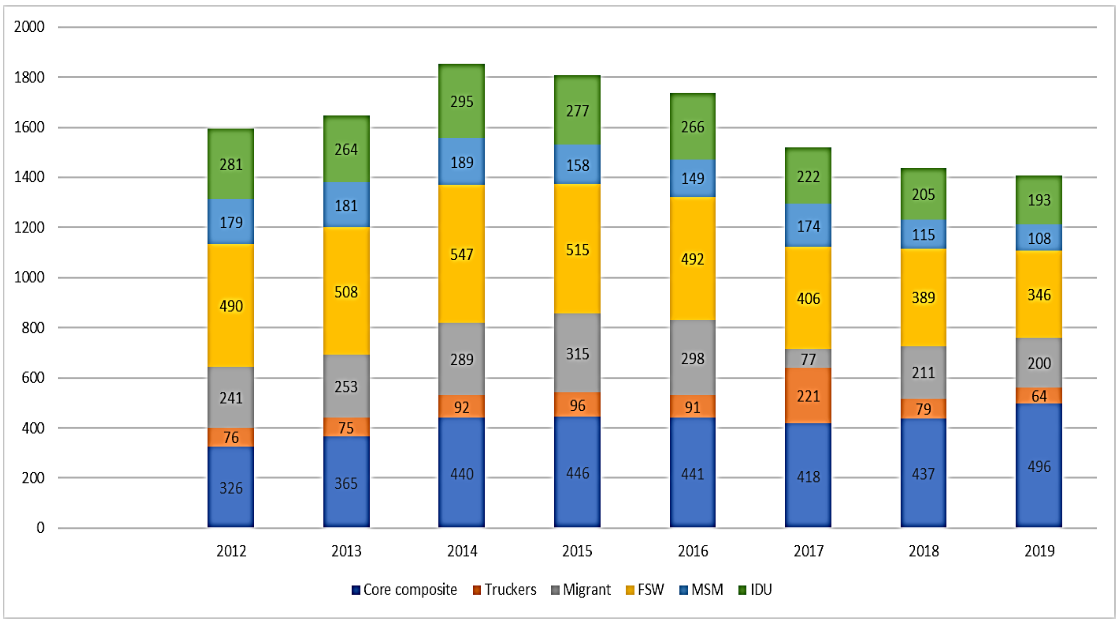
Table 2.5

State-Based Coverage of HRGs for Himachal Pradesh and Neighbours (NACO, 2019)

STATE	Core Group				Bridge Population	
	FSW	MSM	IDU	TG	SMM	LDT
Bihar	12,021	2,950	4,385	-	-	26,627
Chandigarh	3,311	2,470	1,690	108	70,524	4,466
Delhi	52,458	18,487	14,348	8,721	837,453	208,459
Haryana	8,430	4,688	2,547	-	-	-
Himachal Pradesh	**5,988**	**479**	**489**	**-**	**63,290**	**-**
Jammu Kashmir	1,830	464	2,271	-	-	-
Punjab	15,054	3,539	15,477	-	140,747	61,893
Rajasthan	16,009	5,446	1,642	631	226,384	79,718
Uttar Pradesh	22,703	7,505	19,109	4,228	77,816	71,820
Uttarakhand	5,410	1,484	1,869	76	132,214	196,609
All India	**776,237**	**265,740**	**151,945**	**41,176**	**7,660,619**	**2,603,528**

Figure 2.17

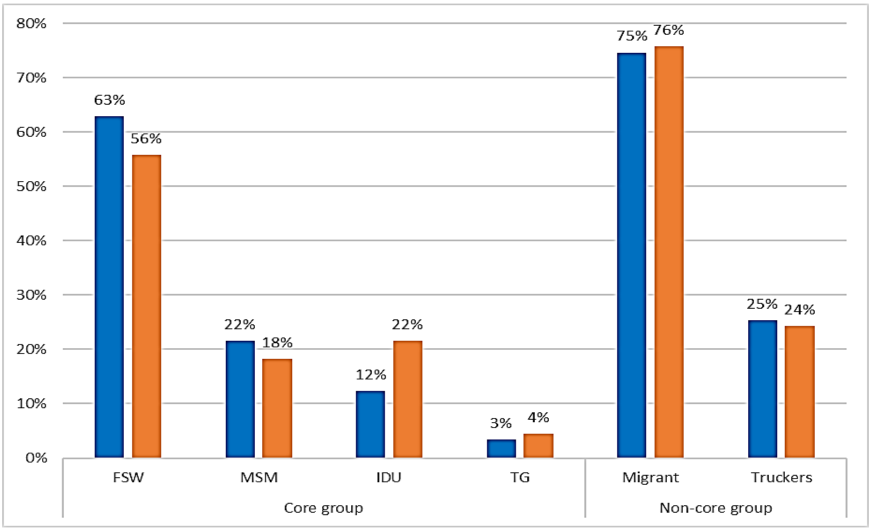
Comparing Targeted Intervention Projects in India (all states) for HRGs (NACO, 2019)



The distribution of the targeted intervention projects among core and non-core groups matches the proportion of HRGs within that group. For instance, FSWs form 63% of the core-HRGs while they are allotted lesser (56%) projects; while IDUs who formed lesser (11%) of the core HRGs were allotted higher (22%) projects (Figure 2.18). Targeted interventions covered more than 75% of core HRGs, but less than 60% HRGs accessed counselling and testing services (NACO, 2019), leading to ineffective counselling programmes.

Figure 2.18.

Comparison of Allocated (blue) Versus Implemented (orange) Targeted Intervention Project for Core and Non-core HRGs (NACO, 2019)



*Adjusted percentages with 496 core composite Targetted Intervensions

Similarly, Table 2.6 compares the number of targeted interventions in Himachal Pradesh and neighbouring states (NACO, 2019). The programme statistics revealed that HRGs who have been associated with targeted interventions for more than 5 years were tested regularly, and consistent efforts were made to keep their HIV status negative across the majority of the states. However, higher HIV positivity remained a concern among IDUs and the HTG population. In fact, due to their constant mobility and unwillingness to visit the HIV counselling and testing centre, several IDUs and bridge population clients never got tested. (NACO 2019). The national figures highlighted that

67% of migrants who were referred to do counselling and testing never went for HIV testing.

Table 2.6

Targeted Intervention Projects in Himachal Pradesh and Neighbouring States (NACO, 2019)

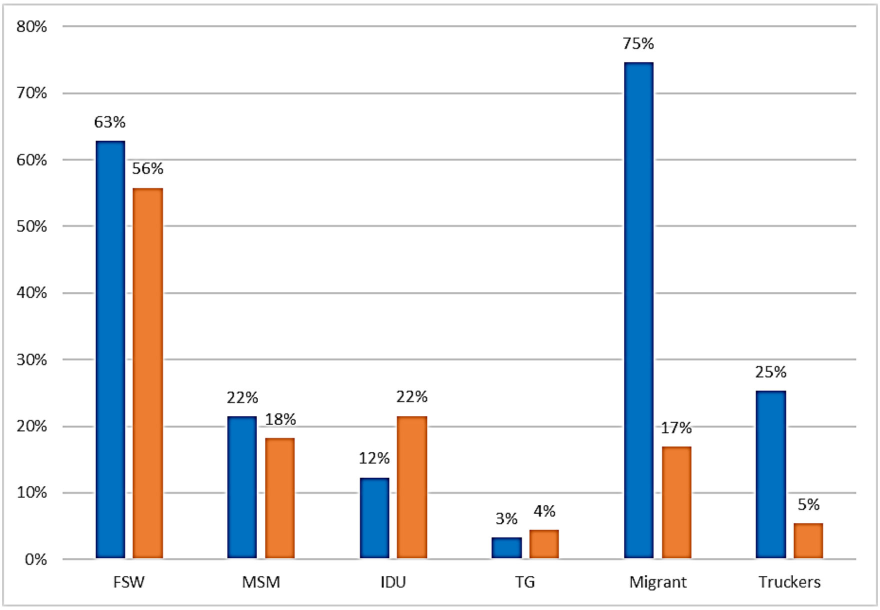
STATES	FSW	MSM	IDU	HTG	CC*	SMM	LDTS	Total
Bihar	3	2	8	-	11	-	1	25
Chandigarh	4	2	2	-	1	2	1	12
Delhi	31	11	13	6	-	13	4	78
Haryana	2	1	1	-	19	-	-	23
Himachal Pradesh	**9**	**-**	**1**	**-**	**5**	**2**	**-**	**17**
Jammu Kashmir	2	1	5	-	3	2	-	14
Punjab	10	3	18	-	24	5	2	62
Rajasthan	6	1	2	2	17	6	3	37
Uttar Pradesh	3	-	8	2	57	6	5	81
Uttarakhand	6	-	4	-	7	4	3	24
All India	**346**	**108**	**193**	**36**	**496**	**200**	**64**	**1,443**

***CC – CORE COMPOSITE PROJECTS ARE TARGETED ONLY TOWARDS CORE-HRGS (NACO, 2007B)**

Targeted intervention projects aimed at migrants cover more population compared to those targeting HRGs. Migrants who form 75% of the total non-core HRGs were allocated only 17% of the targeted interventions (Figure 2.19). This meant that only 200 projects served 7.7 million migrants, covering 40,000 non-core HRGs per targeted intervention project. In contrast, 1,126 projects were allocated to 1.2 million core-HRGs, covering approximately 1000 HRGs per project (NACO, 2019), disproportionately targeting migrant HRGs. These figures indicate a lacuna in programme planning and implementation, leading to ineffective programme delivery in Una due to high workload on counselling centres that are already short of staff.

Figure 2.19

HRG Percentage Compared with Targeted Intervention Project Allocations Among All HRGs (NACO, 2019)*



*Adjusted percentages with 496 core composite Targetted Interventions

NACP has also made consistent efforts to scale up HIV prevention and control efforts for core and non-core HRGs, and improve the coverage in high priority districts (NACO, 2021, n.d.). However, based on the NACP reports from 2014-19, Himachal Pradesh experienced a significant reduction in allocated TI projects, and could implement only 50% of the targeted interventions compared to what was allocated (NACO, 2014-19). Though the financial documents for these projects are not available in the public domain, it is clear that these reductions were due to more attention to high priority states, and Himachal Pradesh was not one of them. Moreover, most targeted intervention projects were for FSWs in 2018-19 and the state struggled to support MSMs, LDTs, and HTG.

With a federalist financing model, the state programme has no autonomy to choose which districts or HRG groups they prioritise unless the last report indicates it. Social and political factors such as interstate migration, personal preferences, discrimination, language, culture, and religion are not considered in programme reporting indicating a gap in measuring the programme’s effectiveness.

As per the Census (2011), one-third of population in Himachal Pradesh consisted of migrants from nearby states. Himachal Pradesh received a higher migration from Punjab, followed by Uttar Pradesh, Delhi, Bihar, Haryana, and Uttarakhand (Das and Saha, 2013). Since 2012, the HIV control programme in Himachal Pradesh has given more attention to the migrant population. In 2018-19, migrants formed 90% of the targeted HRGs, followed by 8% FSWs and 1% each IDUs and MSM (Table 2.7) (NACO, 2019). These figures were identical to the HRG coverage from neighbouring states (Figure 2.20) (NACO, 2019). Another surprising information from the reports was that Una district had no HTG (Initial. Surname, personal communication, day, month, year).

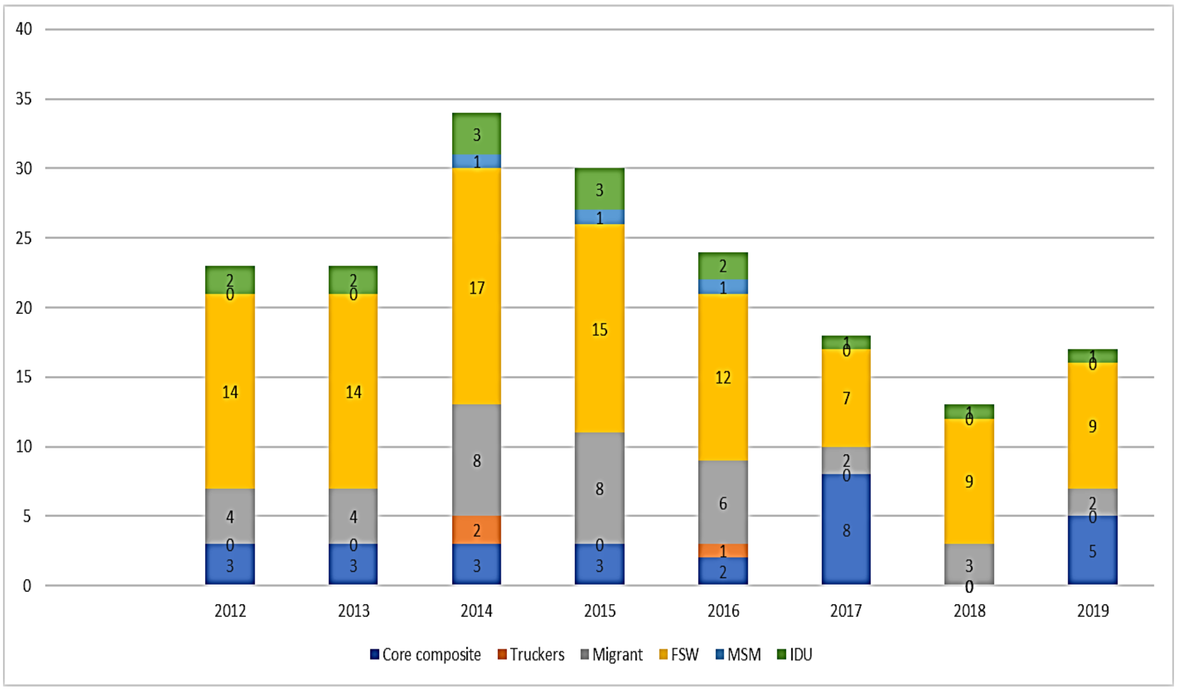
Table 2.7

HRG Targets and Coverage Counts for Himachal Pradesh (NACO, 2014-19)

	2014 (Targets)	**2015**	**2016**	**2017**	**2018**	**2019**
FSW	8,900	8,853	-	4,227	5,159	5,988
MSM	800	459	-	474	530	479
IDU	1,100	790	-	318	313	489
LTD	12,000	12,516	-	-	-	-
Migrants	94,000	94,000	64,000	15,000	4,252	63,290

Figure 2.20

Targeted Intervention Projects Between Different HRGs of Himachal Pradesh Based on NACP Reports 2012-19



The NACP IV (2007-12) planned to implement 34 target intervention programmes for HRGs and the bridge population in Himachal Pradesh . Based on 2014 targets, it aimed to cover 8900 FSWs, 800 MSM, 1,100 IDUs, 94,000 migrants, and 12,000 truckers (NACO, 2014). However, since 2015, the HP state programme has not been able to effectively meet its targets. The recent programme report showed that only 17 targeted intervention projects were functional in Himachal Pradesh, achieving only 50% of the 2014 targets. Furthermore, HPSACS allocated 53% of these projects to FSWs, 12% to migrants, and 30% were designated as core composite projects that again served MSM and FSWs (HPSACS, 2018). Each targeted intervention for FSWs covered 500 people, significantly lower than the national average of 1,000 per project. The state authorities allocated only one project (5%) to IDUs, while no project was allocated to MSMs, HTG, or LDTs. In contrast to Himachal Pradesh, the national targeted intervention allocation was 22% for IDUs,8% for MSM, and 5% for LDTs (NACO, 2019). Usually, these project allocations are based on the target population reported by the state to NACO; however, no published information on how HPSACS allocated targeted intervention projects to HRGs has been found.

There is no current information on how effectively the state delivered services to MSMs, HTG, and LDTs. Perhaps, the core composite projects included MSMs and HTG in their coverage. These core composites were additional projects that targeted HRGs in a combined fashion (NACO, 2019). However, the absence of designated targeted intervention projects indicated that either the state had less population of MSM, HTG, or LDTs or the state HIV programme was ignoring these three HRGs. Furthermore, two-thirds of targeted intervention projects undertaken in Himachal Pradesh in 2016 showed 60% performance, while the remaining one-third were under-performing (NACO, 2017b). This figure was significantly higher than the national average, which amounted to one-fifth of the total targeted interventions underperforming (NACO, 2017a).

2.5. Critiquing Effectiveness of Programme Outcomes

India lags behind its Asian counterparts in awareness levels and implementation of HIV prevention methods. By 2020, it was expected that 90% of all PLHIV will know their HIV status, and 90% of those diagnosed positive will receive sustained HIV treatment in India. However, the latest report by UNAIDS reported that by 2018 only 79% of PLHIV knew about their HIV status, and 56% were on HIV treatment in India (UNAIDS, 2018). The report further highlighted that the knowledge of HIV status among HRGs was significantly lower than targeted figures (UNAIDS, 2018). After several years of targeted interventions, only 68.6% of FSWs, 67.6% HTG, and 64.8% MSM knew about their HIV status; while only half of IDUs were aware of their HIV status (UNAIDS, 2018). These figures suggested that India may take longer to achieve its 2020 targets. In 2016, in India, the knowledge of HIV prevention among young women aged 15–24 years was 21.7% and amongst men was 31.5% . The Indian figures were significantly lower than its neighbouring countries funded by UNAIDS (2018) for their HIV prevention and control programmes (Malaysia, Thailand, Vietnam, and Cambodia).

Furthermore, the number of IDUs using sterile injecting equipment at the most recent injection in 2015 was 86.4%, and no recent data for succeeding years were available. However, 2017 figures stated that the remedial treatment for injecting drug use had a minimal national coverage amounting to 19% for OST with no safe injection rooms available for injecting drugs to IDUs (UNAIDS, 2018). Among HRGs in India, the overall rate of condom use was the highest among FSWs (90.8%), followed by MSM (83.9%), HTG (67.6%), and IDUs (77.4%), which were considerably higher than the neighbouring Asian countries. However, condom use during higher-risk sex (with a non-marital, non-cohabiting partner) was 40.8% in men, while no data were available for women. These figures were lower than Nepal and Thailand whom UNAIDS also fund for their HIV programmes.

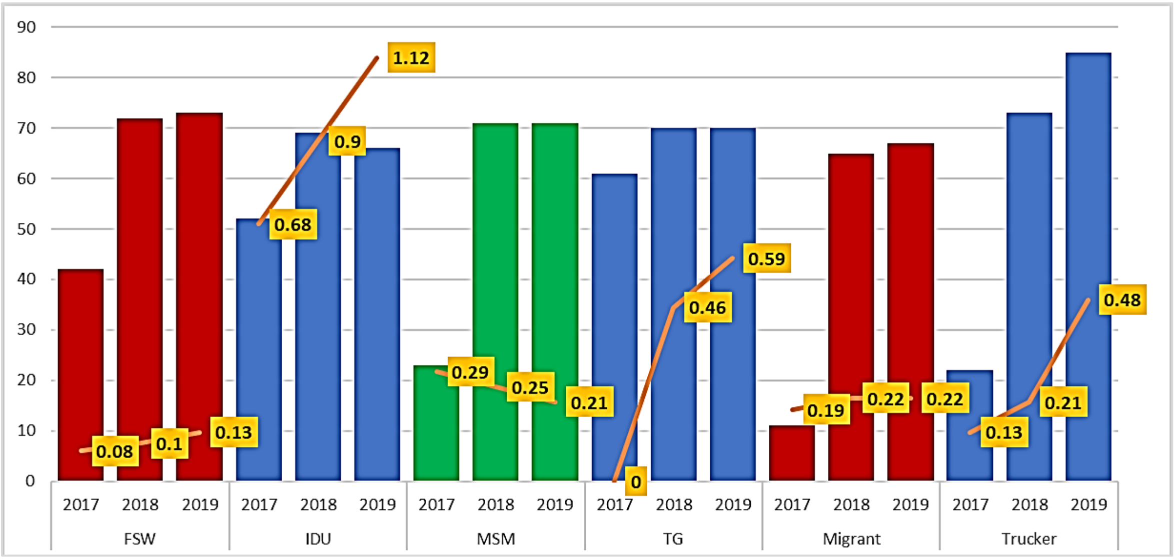
NACO (2021) reported that one-fourth of PLHIVs remain untested. In 2019, one-fourth of total HRGs and one-third for migrants and IDUs had never accessed HIV counselling and testing services. Only 66% of referred IDUs reached counselling and testing centres for testing, the lowest among all HRGs. Interestingly, some Indian districts had limited counselling and testing centres, impeding access to prevention and testing services. Available centres lacked proper infrastructure and facilities to provide confidential counselling sessions. NACO (2019) stated that HIV counsellors were utilised to count the remaining pills of the client’s HIV treatment as part of their role, which means that counsellors would measure medication adherence. Where the guidelines advise 25-30 minutes for each counselling session, several counsellors could only devote 5 minutes for each pre-test counselling session due to heavy workload. Despite continuous efforts, the number of those receiving post-test counselling has remained at its lowest in 2019. Surprisingly, NACO (2019) still expects that community-based HIV testing will eventually address these counselling related gaps.

Per the NACO guidelines, all core HRGs should be tested for HIV once every 6 months. As discussed previously, the HIV programme in India was revised by NACO in every phase to keep pace with the WHO guidelines which recommended a client-initiated voluntary HIV counselling and testing service for all HRGs. In 2021, India had 33,220 counselling and testing centres providing services mainly for HRGs and pregnant mothers. In 2019-20, 29.2 million clients were tested for HIV, of which 168,000 were diagnosed as positive, bringing HIV seropositivity to 0.57% (NACO, 2021). However, of those who tested positive, only 3% were referred from the targeted intervention for HRGs. No data were available on classification based on CD4 count or viral load testing, which could have clarified the behaviour risk patterns (NACO, 2017a). This may indicates a large number of HRGs not disclosing their identities while visiting testing centres adding up to the proportion of visits by the general populace (Figure. 2.21).

The columns in Figure 2.21 denote the percentage of HRGs tested against those covered under targeted intervention projects, while the line denotes HIV seropositivity among those tested. Although NACP claimed that the testing percentage across all groups was consistent over the reporting period, the data state otherwise (NACO 2017-19). The testing percentage among IDUs decreased by 4% in 2019 compared to 2018, meaning fewer IDUs visited testing centres. Furthermore, seropositivity amongst HRGs increased for all groups except MSM (Figure 2.21). This was perhaps due to higher literacy, and more HIV prevention awareness levels in MSM reported earlier in the behavioural survey (Paranjape, Ramakrishnan and George, 2012). However, no recent data were found to support this claim.

Figure 2.21

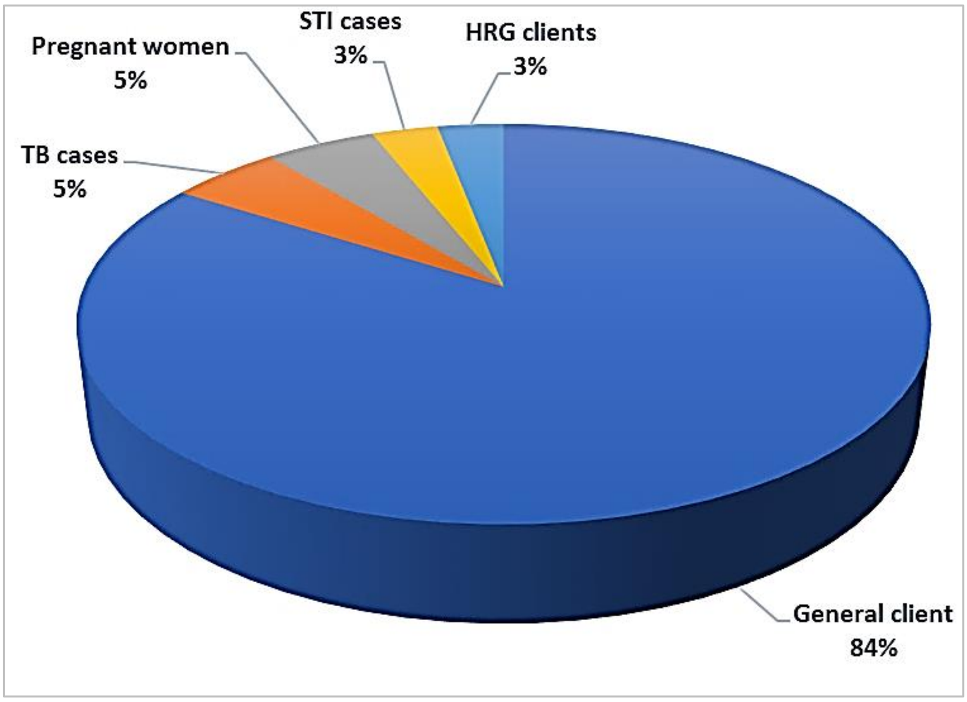
Percentage of HRGs Tested Against Their Seropositivity (NACO 2017-19)



The referrals from tuberculosis testing units and antenatal clinics constituted 5% positives among clients visiting testing centres. The STI clinic attendees constituted 3% positive cases (Figure 2.22), while the remaining 84% formed an uncategorised mixed pool of people whose detailed analysis of socio-demographic, occupation, and other personal characteristics was never done. This inference reconfirms that several HRGs were tested under the general category supporting the arguments from previous sections.

Figure. 2.22

Distribution of Clients Based on Visits for HIV Testing (NACO, 2017a)



In 2020, the number of testing centres increased to 33,220; mainly concentrating on increased testing with lesser importance given to improvement of counselling services. The newer testing centres are facility integrated which means they are situated within the premises of public hospital or medical centres. Such facility integrated testing centres have less privacy than standalone counselling and testing centres usually located closer to the HRG communities. However, the 2021 NACO report indicated a higher stress upon increasing more facility integrated centres over standalone in both private and public sector.

In addition, the national AIDS strategic plan envisages screening up to 127 million individuals annually by 2024 and strengthen both facilities based and outreach services. To improve the efficiency and bridge the estimated shortfall in counsellors from current resources, standalone counselling and testing centres with low testing load and detection rate will be converted to facility integrated or singled staffed testing centre where one person will act as a counsellor as well as auxiliary staff. This has further resulted in decrease in standalone centres from 5,547 in 2017-18 to 5,330 in 2019-20, and a simultaneous increase in the number of facilities integrated centres.

Since the colonial era, the understandings of health in India have been strongly influenced by biomedical concepts of health where diagnosis and treatment have the highest importance (Limb, 2011; Patil et al., 2002), making it difficult to attract resources for the HIV counselling programme (Avert, 2014). For instance, the majority of funds from the NACP's budget (2017-18) amounting to USD 636 million were allocated for treatment purposes, and the counselling component was neglected (Figure 2.23) (NACO, 2017a). The counselling expenses mainly comprised the salaries of HIV counsellors and staff. Salaries equated to 63% of the total funds received under the basic services division, while 10% were used to purchase HIV testing kits (Figure 2.24). Perhaps, the reduced funding was due to the absence of appreciation towards HIV counselling and its effects on improving the lives of HRGs.

Figure 2.23

Distribution of 2017-18 Budget into Various NACP Services (NACO, 2017a)

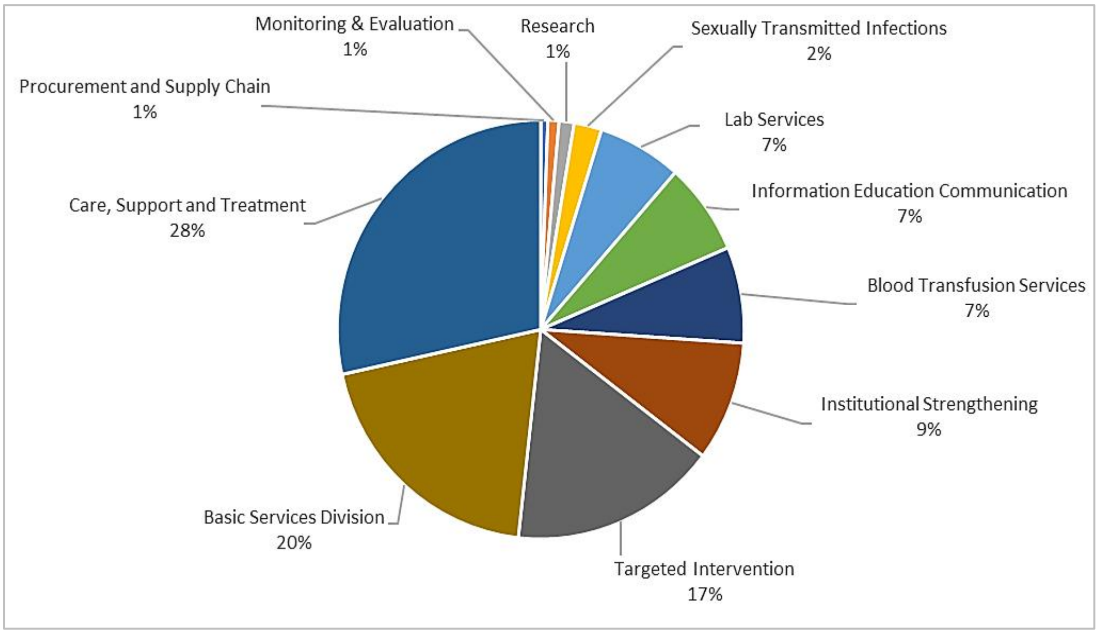
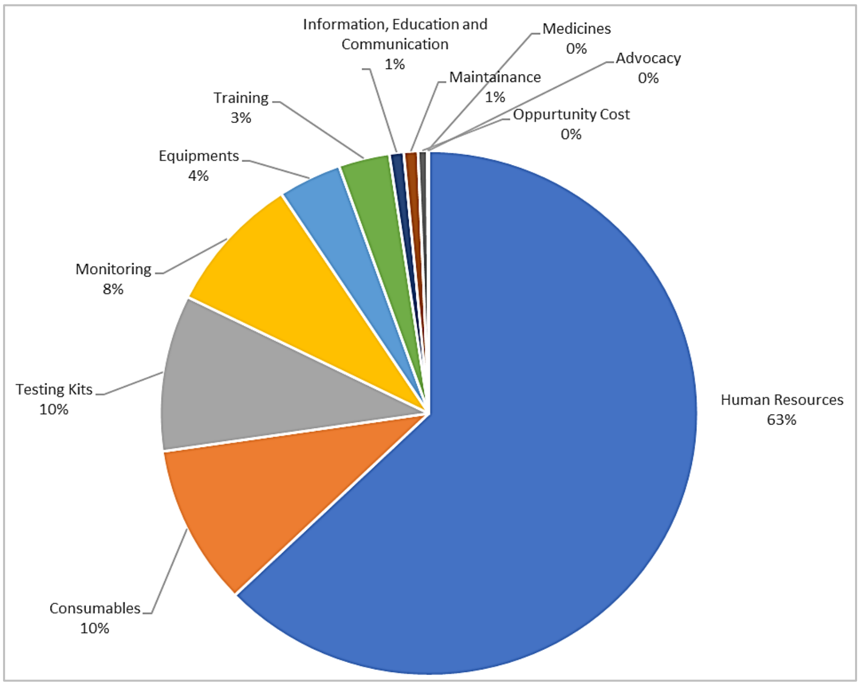


Figure 2.24

2017-18 Budget Allocation to Various Components Within Basic Services (NACO, 2017a)



It is also worth noting that the effectiveness of HIV counselling in India has never been evaluated qualitatively. Several studies have indicated both quantitative (Farquhar et al., 2004; Grinstead et al., 2001; Sangiwa et al., 2000) and qualitative (Adedimeji et al., 2012; Cocohoba et al., 2013) research methods are essential to assess the effectiveness of HIV counselling. However, NACP’s progress reports were quantitative, ignoring the qualitative aspects of HIV counselling services that are core to any psychosocial support services (GoI, 2011a; NACO, 2014; UNGASS, 2010; UNAIDS, 2019a, 2019b). Without an effective evaluation method, the programme has been mainly ignored by NACO; thus, receiving lesser funds for its effective implementation.

India’s commitment to the United Nations for ‘ending the AIDS epidemic as a public health threat by 2030’ was in line with the Sustainable Development Goals

(SDGs). Meeting SDGs has always depended on early HIV detection and quick access to treatment and care. The National Strategic Plan (2017-24) for NACP (NACO, 2017c) indicated that India needs better prevention and detection services to cover gaps in HIV case detection rates. However, reported figures indicated these goals as hard to achieve and reported gaps in HIV detection and access to treatment. These reports did not report data on service usage patterns related to the programme. Furthermore, there were no data on counselling service utilisation from 2018 to 2021.

2.6. Summary

The top-down nature of donors, inadequate appreciation of the programmes, issues around the Indian government's decision making, the views of vital stakeholders in HIV counselling including those of the clients and counsellors, have been neglected in the operation of the HIV counselling programme (NACO, 2014). There has been a dearth of studies in the Indian context that acknowledge politics and power of policy observed in the programme which has concentrated more on performance indicators. The technical approach to HIV has overpowered its socioeconomic, cultural, religious, and political associations. The various gaps in the programme discussed in this chapter make it compelling for public health researchers to look beyond the boundaries of the programme as laid in its guidelines and reports.

CHAPTER 3 – A CRITICAL POLICY REVIEW

BARRIERS TO EFFECTIVENESS OF INDIAN HIV COUNSELLING PROGRAMME

> *In the euphoria after the cold war, there was a misplaced notion that United Nations could solve every problem anywhere. The reality is that international institutions like the UN can only be as effective as their members allow them to be.*
>
> Late. Atal Bihari Vajpayee (2003)
> Ex-Indian Prime Minister

3.1. Introduction

The previous chapter set out a social epidemiological analysis of the context of the research topic—the effectiveness of India's HIV counselling programme—drawing from statistical sources and government and donor agency reports. It proposed that the Indian government has struggled to manage this epidemic since its start and emphasised the need to find effective ways to measure the performance and control of the epidemic in high-risk populations. Chapter 2 also explored the measurement of programme performance through surveillance, but this does not, by itself, capture the complex nature of the epidemic and epidemic response, with historical, political, and social factors playing a significant role in this public health problem.

In Chapter 3, there is a shift in the discourse to explore the historical and policy context relating to the effectiveness of the Indian HIV counselling programme. The discourse adopts a critical lens to consider the social construction of knowledge through power relationships. This approach recognises the impact of history—pre- and post-colonial events in health systems, and public health and the Indian HIV counselling programme's journey—in shaping programme effectiveness today. It answers the first research question on the evolution of the Indian HIV counselling programme and the events that shaped its effectiveness.

As discussed in Chapter 1, current measurements of the effectiveness of the HIV programme utilise a functional management model for measuring programme effectiveness rather than a systems-based or holistic and culturally adaptive model. This critical policy review, alongside the social epidemiology chapter, allows for a fuller critique of the evolution of the HIV counselling programme in India. It includes the experiences of pre-independence colonisation and the impact of the post-independence donor-financed vertical programme model on public health, and the impacts of these historical features on the measurement of programme effectiveness. The review is based on the underlying notion informed by critical theory that there is no one version of events. Indeed, an epidemiological assessment often presents the situation in a privileged way through the voices of the powerful. It often ignores issues of not just power but the unique and various set of factors that shape different programmes in different places (McArthur, 2021). Therefore, as a critical policy analyst, the researchers has attempted to explore the silenced and hidden versions or challenge the dominant, often medicalised version of, health policy history (Brewer, 2014; Young, 1999).

This critical policy analysis reveals patterns of long-term social interactions that impacted the programme while simultaneously showing how these social structures that still dominate it have influenced the measurement of effectiveness. The main areas of this critical policy review include principles and practice of PHP effectiveness (3.3); the public health systems of medicine (ISM) in India and how these have been neglected from colonial times onwards (3.4); foundations of PHP effectiveness in India (3.5); verticality as a solution for Indian public health (3.6); vertical programmes and the NACP (3.7), and aspects of programme implementation in the current post-colonial era (3.8).

3.2. Literature Search Strategy

There has been a dearth of studies in the Indian context that acknowledge the politics and power of policy observed in PHPs or critique the way programme effectiveness is measured. This critical policy review followed a selective approach to mining articles, utilising keyword search strategies to consider relevant research and methodologically appraising and synthesising chosen articles (Hart, 2005). The literature was selected using a range of databases and publications in English, the official language used in Indian publications. The literature available on the evolution of India’s public health in pre- and post-colonial contexts, India’s HIV counselling programme, its donor dependence, and the counselling programme, in particular, were searched. This helped to provide evidence for the review relating to the first research sub-question: “How has the Indian HIV counselling programme evolved and how has that shaped the programme effectiveness of today?”.

BioMed, PubMed, EBSCOhost, ProQuest, Elsevier, Scopus, Google Scholar, and other relevant databases were used to identify literature using the following terms: “HIV counselling AND India”, “public health AND HIV and India”, “India AND public health AND colonisation”, “British colonisation AND Indian health systems”, “donor dependence OR verticality AND Indian public health”, “economic reforms AND Indian public health”, “India AND indigenous health systems”, “HIV AND Ayush (Ayurveda, Yoga, Unani, Siddha and Homoeopathy)”, and “India AND biomedicine”. Literature were searched and sorted by year of publication ranging from 1985 to 2021. The search included five types of publications: research articles, books, reports, media articles, and grey literature such as institutional reports. However, several articles were also considered based on their scope in covering the research question and the value that certain publications by prominent public health policy researchers can offer (Hart, 2005) in enhancing the critical nature of the section.

The total sources of 300+ articles and reports were reduced to 150 relevant sources, including 104 journal articles and 46 from a combination of books, reports, and conference papers, by process of considering their relevance to the research question based on a broad understanding of the history of public health and colonisation and the HIV counselling programme in India, all of which were used in this chapter. I drew on my experience from past employment in the Indian HIV programme.

3.3. Principles and Practice of PHP Effectiveness

Programme effectiveness has been described as the ability to produce the desired result within the dimensions of performance, usually measured quantifiably (Ranjithlal, 2019; Kumar, 2011). A programme is defined as a set of goal-oriented and time-limited activities managed in a coordinated manner to effectively deliver their intended outcomes (Project Management Institute [PMI], 2013). Specific to public health, such programmes are organised for public health actions, such as HIV counselling services, with an outcome to achieve its goals and positively affect health (Milstein and Wetterhall, 1999). In terms of PHPs, effectiveness relates to measuring health-related outcomes, while efficiency measures the cost or value of such outcomes against given resources (Haddix et al., 2002). In terms of PHP effectiveness, measurements relate to achieving desired quantifiable outcomes, usually laid down in the programme guidelines, concerned with health outcomes and value for money (Kelly and Killoran, 2009).

In the case of PHPs, typically funded by governments, outcomes are often established by the funding department or agency (Bialek et al., 2017). Funders weigh risks and benefits for the service users against the costs signifying the performance of a programme. Cost-effectiveness becomes a crucial characteristic for evaluating quality (Freeman, 1999). Cost-effectiveness is a measure of how investments in a programme contribute towards better health outputs (Neumann et al., 2016). Frieden (2014) described performance management based on the effective utilisation of investments as an essential component for PHP implementation, where measuring programme effectiveness has been influenced by principles of profitability against investments.

For newly emerging infectious diseases and the increasing incidences of noncommunicable diseases, funds for PHPs are targeted toward developing better diagnostics, medicines, medical devices, and vaccines. Utilisation rates, adherence, and coverage of these drugs, vaccines, and devices have become the indices for measuring the cost-effectiveness of PHPs. Thus, PHPs and measures of programme effectiveness are strongly influenced by management concepts informing their development and implementation (Schoon et al., 2018). Effectiveness is primarily associated with measuring quantifiable inputs and achieving desired outcomes based on quantifiable outputs (Smith and Clark, 2006). However, these principles have been criticised for ignoring historical, social, cultural, and political issues (Lang, 2005; De Maeseneer, 2007), and emphasising institution-driven rather than user-driven criteria (Hunter, 2016).

Often what shapes health outcomes are complex and contextual factors, and it is challenging to design quantitative measurements that capture complexity and context. For instance, social factors are frequently left out of evaluation processes; yet, ignoring social factors can fail to capture health inequalities, especially for high-risk people. Lang (2005) argued that ignoring social contexts results in adverse health events and lower quality of disease control in PHPs, adding that equitable implementation of evidence-based health care should consider quantitative as well as qualitative evidence.

NACP utilises programme management concepts in its design, implementation, and measuring effectiveness, which has been evaluated quantitatively. As discussed in section 2.5, effectiveness should be reported in both quantitative and qualitative fashion while NACP reports progress quantitatively, ignoring the social aspects of HIV counselling. This indicates that the current functional programme effectiveness assumes the normative programme model as optimum and does not consider other models. Qualitative evaluation of effectiveness utilising critical policy can expound social factors while appreciating the power dynamics within the system. It allows the researcher to evaluate these factors to their most essential parts, helping determine the accuracy and truthfulness of the existing measures of effectiveness.

The current HIV programme management evaluation process only considers the current PHP normative model. They do not take into consideration other public health models or systems appropriate to the context. This thesis refers to such an approach as intrinsic or functional model of measuring programme effectiveness. The model is purely quantitative and does not include ways of measuring effectiveness that are outside the programme management guidelines. Vertical programmes solely rely on these guidelines by measuring effectiveness through crucial performance indicators ignoring the social factors that make people vulnerable to HIV infection and its consequences. The Indian public health system also follows an intrinsic model of programme management effectiveness which is dominated by mainstream allopathic system of treatment and neglects existing Indian systems of medicine (ISM). This issue is explored in the next section.

3.4. Public Health Systems of Medicine in India

This section explores the role of British colonisation in developing the Indian public health system, particularly emphasising the interplay of various systems of medicine during pre- and post-independence eras. A critical policy perspective allows the exploration of Indian history that shaped its public health system, which it is argued has created a particular set of circumstances that continue to influence responses to HIV/AIDS.

3.5. ISM in Pre-colonial and Colonial Eras

The ISM, currently referred to as AYUSH [*Ayurveda*, *Yoga* and naturopathy, *Unani*, *Siddha*, *Sowa-Rigpa* and homoeopathy], are well-known global traditional systems of medicine with ancient histories (Ministry of Ayush, 2023; NITI Aayog, 2021; Prasad, 2002). The literature emphasises the importance of indigenous/traditional systems of medicine in meeting public health needs (Park, Yi and Kwon, 2022) as well as for HIV counselling programme (Nastasi et al., 2007; Saggurti et al., 2013).

In the years of overlap between the Mughal dynasties and British rule, various ISM prospered, indicating the ruler's interest in that system (Prasad, 2002). *Ayurveda*, *Yoga* and *Siddha* originated in India, *Unani* originated in Greece, *Sowa-Rigpa* from Tibet, and homoeopathy originated in Germany (Prasad, 2002). Of all these, *Ayurveda*, a herb-based treatment, is the oldest and most widespread ISM still widely used in India today (Srinivasan and Sugumar, 2017). Of great significance, *yoga*, another longstanding ISM, is based on physical exercise, a healthy lifestyle, and meditation (Singleton, 2010). *Unani*, *Siddha* and *Sowa-Rigpa* have influences from *Ayurveda*. These systems also involve a combination of herb-based treatment and meditation (Muthiah et al., 2019).

3.5.1 Colonial Authority and ISM

In India, since 1986, the HIV pandemic has been managed by the allopathic system of medicine (Solomon, Solomon and Ganesh, 2006). Neither AYUSH nor other treatment paradigms have been given a place in the programme or mainstream HIV research. The following section discusses how this situation came about.

With colonial rule established in the early 19th century, the use of allopathy for population-based treatment was considered an effective solution for managing epidemics. During colonial times, severe epidemics ravaged the country, due to which public health became a significant concern for administrators and the civilian population (Bala, 2012). Allopathy was the only system known to British and emerged as a dominant medical knowledge system (Honavar, 2019). It is defined as the suppression of disease symptoms by an agent producing the opposite symptoms (Bhardwaj, 2010; Stewart, 1968)**.** In the absence of a uniform system of medicine, allopathic treatment catered for the demands of different religions, cultures, and regions (Adams, 2007).

The British physicians who assumed broader academic positions in the Indian public health system made decisions for these large-scale treatment methods. With the establishment of the first Indian health care statute in 1914 (The Tamil Nadu Medical Registration Act, 1914) legitimising several professionals with degrees in allopathy, it became the only nationally recognised system of medicine in India (Sriram, Keshri and Kumbhar, 2021). With increasing epidemics and famines of the late 19th century, and the absence of uniform and structured public health arrangements, allopathic treatment methods were used on a large scale for Indian PHPs (Amrith, 2009).

The colonial administrators were familiar with the type of healthcare that involved regulated hospitals and providing priority services to the British community (Adams, 2007; Spencer, 2003). Though the success of public health lay in active cooperation, such cooperation was impossible, where racial superiority and cultural distance made constructive relations difficult (Bala, 2012). Thus, there has always been a conflict between British and traditional modes of disease control.

After 1947, in the post-independence period, Indian public health adopted western medicine (Amrith, 2007; MoHFW, 2017). Honavar (2019) commented that the government of independent India "effortlessly inherited" this public health system from its colonial rulers, referring to it as "the evidence-based healthcare system deep-rooted in the structures and systems established by the British in the pre-independence era" (p. 1259). This system started as a disease control measure for colonial workers in the 19th century. Nevertheless, by the 20th century, allopathy had dominated all developing health systems around the world through the dominance of medical training and professionalism and the rise of western pharmaceutical industries (Honavar, 2019). Subsequently, the health systems of post-independence India as a developing nation were still subject to post-colonial norms.

There is little doubt that health has not been India's priority since independence. Funding for Indian public health has been referred to as "grossly inadequate" to address the needs of its citizens due to higher infrastructural and developmental investments (Amrith, 2007). Having a widely adopted and accepted allopathic system was considered by the Indian government as a way to attract donor funding. Donors were willing to fund health packages delivered by donor-designed programmes. These invariably involved allopathic medicine and empirical systems measuring outcomes (Amrith, 2009).

While AYUSH's reliance on ancient Indian heritage for scientific wisdom has been referred to as illogical reliance (Shaikh, 2018), allopathic practitioners continually criticise ISM for lacking scientific evidence of success. The Indian government has been criticised for using public funds to develop AYUSH. These systems also face regional and religious divides; thus, the situation is complex. Hindus tended to used *Ayurveda* and *yoga,* while Muslims used U*nani* systems (Srinivasan and Sugumar, 2017). Despite these discrepancies, AYUSH continues to be used by residents across India. It enjoys a unique position in the Indian public health system but is still not wholly integrated into the mainstream government public health system (Shaikh, 2018).

The conflict between allopathy and ISM has continus. Allopathy is underpinned by biomedical models, germ theory, and biological plausibility; whereas the ISM are referred to as pseudo-scientific or alternative systems (Rudra et al., 2017). Physicians from western systems of medicine neglect other treatment approaches that can contribute to health; for example, those used by homoeopathy, *dosha*-neural models of *Ayurveda* and *Unani*, naturopathic holistic healing approaches, and biopsychosocial models adopted by other systems. AYUSH physicians are often criticised for their lack of scientific evidence, derogatorily referred to as "pseudo health practices", with little distinction from quackery (Patwardhan, 2015). Patient data from AYUSH practices are often not included when reporting the status of HIV and other STIs (Patel and Majumdar, 2019).

British colonial policies instituted allopathy for post-independent public health. ISM experienced marginalisation due to these policies (Bala, 2012). Indian public health has always witnessed constant tension between the scientists and clinicians of allopathic and AYUSH systems, privileged by different levels of recognition these systems receive. Most often, allopathic scientists and clinicians do not find AYUSH systems effective when they evaluate evidence in the same way as allopathic evaluation (Narayana, 2016).

The ongoing domination of intrinsic models of measuring treatment effectiveness has resulted in debates around the inefficacy of ISM treatment. Evidence-based medicine has been criticised for its pitfalls, especially when dealing with complex interventions (Campbell et al., 2000), such as AYUSH, which claims to treat in a holistic and multidimensional manner (Fernandez, 2015). Several measurements of psychological health, physical measurements, and psychosocial changes are required to measure the effectiveness of such interventions. Furthermore, the neo-colonialism in the form of donor and big pharma industry has overlooked the

ISM's role on Indian public health system (Bala, 2012). Therefore, more innovations in clinical research and support from government are required to establish the efficacy of such complex treatment methods (Gautama, 2021).

AYUSH provides process-based care customised to the client, maintaining the personalisation that is missing in allopathy; as such, it is highly relevant to a programme such as counselling. The social world of the client is considered an active factor in health and disease, which, again, is the definition of holistic medicine (Campbell et al., 2000). HIV is a complex disease that affects many facets of the human body (social, economic, physical, emotional, spiritual) and an individual's life, making retention goals in care and adherence to treatment difficult to achieve (Chinyandura et al., 2022). When AYUSH interventions such as yogic therapy and herbal medicines were applied, patients showed an improved ability to manage their health and overall sense of well-being even when they returned to their usual life context (Conboy, Edshteyn and Garivaltis, 2009). Holistic patient-centred approaches for providing care for PLHIVs bind together these aspects and potentially improve retention in care and treatment adherence. However, AYUSH systems have not been applied in any aspects of the national counselling programme. The ISM-related training that the counsellors receive is limited and geared toward promoting medication adherence (Nastasi et al., 2007).

3.6. Foundations of PHP Effectiveness in India

India has faced a series of economic and health reforms since independence shaping its public health system. Indian public health has always been measured normatively based on cost-effectiveness and the criteria set by funders. The following section traces the path of the Indian public health system and the role of economic reforms in shaping it.

As discussed earlier, although modern India’s social and economic policy planning happened after independence in 1947, the blueprint of India’s public health system was defined in the colonial era (Banerji, 2001). Like the Indian constitution, these initial Indian public health policies firmly adopted the then-British policies.

As England experienced the adverse effects of its Industrial Revolution, there was a movement toward sanitary reforms and the establishment of public health institutions in the 19th century. During these years, British India established its first Medical College in Calcutta in 1935, which aimed to deliver medical services to British troops (Negandhi, Sharma and Zodpey, 2012). This was followed by the Indian Medical Services (IMS) formation in 1896. By 1919, the public health and sanitation guidelines from the IMS were adopted by the British-occupied provinces. Based on these guidelines, population data on vital statistics were collected and sent to the IMS (Negandhi, Sharma and Zodpey, 2012). The establishment of the institutes for public health during the 1930s was supported by generous donations from the Rockefeller Foundation (Negandhi, Sharma and Zodpey, 2012). These institutes delivered public health knowledge across the country, received mainly by the urban provinces connected via roads, postal, and tele-communications.

The Bhore’s Health Survey and Development Committee of 1943 was highly influenced by the public health system established by the colonial rulers (Wujastyk and Smith, 2013). Sir Joseph William Bhore, an Indian civil servant appointed by the British, charted the course for India’s public health investments and infrastructure. The committee recognised the vast rural-urban disparities in existing public health (Gautham and Shyamprasad, 2010); emphasised integration of curative and preventive medicine; and remodelled health services by developing rural health centres and district hospitals. A further recommendation was to have a single biomedical qualification as the requirement to become a doctor (WHO, 1967). India’s public health foundations were based on the recommendations developed from this national survey data (Sahasrabuddhe, 2016). Though the government promoted individual liberty, social justice, welfare, and secularism (Gehlot, 1991; Indian National Congress, 2018), these indices were never evaluated nor reported by the committee report; therefore, never had an opportunity to directly influence the public health of independent India.

Health was proposed to be funded by state governments, while the centre provided residual funding for public health services (MoHFW, 2011). The state health budgets were directed towards a ‘free for user’ oriented public health system to make it successful in rural areas (Yuk-ping lo, 2015). The Indian government aimed to distribute public health via public-owned and operated health centres using a three-tier public health structure with a bottom-up referral process recommended by the Bhore committee (Duggal, 1991). The number of state-wise centres and staff was proposed to be calculated based on the demographic requirements of that region. ISM were positioned solely at the level of primary health centres and were less funded compared to the allopathic system; similarly, ISM practitioners were compared as lesser than allopathic practitioners (Lakshmi, 2012).

In the first two decades of independence (1947–1967), also called the Golden Two Decades of Public Health in India (Banerji, 2001), life expectancy was reported to have increased by 16 years (Peters et al., 2003) and the infant mortality rate in rural areas dropped by half (Patil, Somasundaram and Goyal, 2002). The three-tiered system proposed by the Bhore committee was finally established in 1975 after the Srivastava committee’s report (Sharma et al., 2016). The committee recommended the establishment of sub-centres for essential public health services, primary health centres for preventive and curative services, and community health centres for specialist services (Negandhi, Sharma and Zodpey, 2012).

Nevertheless, in the first two decades after independence, public health spending became unsustainable due to insufficient domestic funding as the government could not financially support their people’s health or afford the integrated health system (Dayal, 2014). Several states suffered famines, floods, and droughts after independence, weakening the public health infrastructure and adversely impacting funds to support public health. In the 1970s political environment, the approach to public health moved to authoritarian, especially after the internal disturbances during 1975-77. Prime Minister Indira Gandhi was criticised for authoritarian actions and reported human rights violations. For instance, to address the challenge of a rising population, forced mass sterilisation campaigns were conducted from 1975-76 (Dayal, 2014).

The 1970s was also the era when the ideas for development aid emerged worldwide, in tandem with a concern for human rights that address basic human needs. These ideas were in response to Cold War politics and unacceptable poverty levels (Ortiz, 2007). Due to the global political unrest of the continuing Cold War, the World Bank showed concern over the political barriers to implementing primary health care globally (Cairncross, Periès and Cutts, 1997). Thus, funding was directed to those countries that no longer supported communism and were willing to support the United Nations and its initiatives (Ortiz, 2007). Donor assistance laid the foundations of PHPs in developing countries.

Post-independent India was a country struggling both economically and systemically. A significant proportion of the nation’s GDP was required to repay older international debts, which the government had borrowed to mitigate past epidemics, droughts, and famines. By the 1970s, it primarily relied on assistance from a multiplicity of donors, backed mainly by United Nations’ agencies, like the World Bank, for its public health. This marked a shift from government-regulated integrated public health to disease-specific programmes shaped by international donors.

3.7. Verticality: The Solution for Indian Public Health?

In 1978, a WHO-driven primary health care approach, known as comprehensive primary health care, was advocated by several nations as the key to achieving “Health for All” (WHO, 1978). Comprehensive primary care involves interventions dealing with several health problems or diseases. It focuses on an overall improvement in the health of the residents while putting the disease in its social and political context, emphasising community participation and intersectoral collaboration (WHO, 2000). It was designed primarily to target the developing nations that ratified the WHO’s Alma Ata Declaration on Primary Health Care (PHC) in 1978. Every country was advised to deliver publicly funded comprehensive primary health care programmes for its citizens (WHO, 1978). The World Bank and United Nation members supported these programmes as donors and technical advisors (Haines, Horton and Bhutta, 2008). The WHO (1978) proposed that these programmes would cater to the citizens’ basic public health needs and could later be integrated into their existing public health systems (Msuya, 2004; Pisani, 2010).

The Indian government ratified the Alma-Ata declaration of 1978, which was important for receiving support from developed member countries to receive basic health packages for its citizens (Haines, Horton and Bhutta, 2008; WHO, 1978). It was planned that once the Indian economy stabilised, it would start using domestic funds to pay for public health (Msuya, 2004; Pisani, 2010). However, the World Bank and United Nations member states were concerned over the limited success of the WHO’s comprehensive approach and its lack of cost-effectiveness in delivering better health care in developing nations (Cairncross, Periès and Cutts, 1997; Haines, Horton and Bhutta, 2008) as the comprehensive approach needed substantial external assistance and a complex system for channelling funds and measuring the effect of funds on specific targets.

The initial vision of PHC was that of a comprehensive and integrative health care system accessible at community level (Baum et al., 2017). This would benefit developing nations by encouraging democratic participation in health, helping improve social and environmental contexts that create disease and risks for disease. However, this vision was overtaken by a pragmatic call for a more selective approach, although considered initially to be temporary, until developing countries could afford a more comprehensive approach (Baum et al., 2017). Less than a year after the Alma Ata conference, a solution was proposed where donors would target a limited number of diseases concentrating on specific interventions (Haines, Horton and Bhutta, 2008). Seen as an appropriate interim strategy for disease control in developing countries, this approach minimised the broader social change ambitions, marginalised preventive and promotive actions, and emphasised responses to specific diseases or narrowly defined health outcomes (Walsh and Warren, 1980).

The so-called selective primary health care included a package of individual vertical PHPs. Usually, a PHP is described as vertical when it calls for the solution of a given health problem by a system of activities focused on eliminating only the disease of concern with earmarked funding and separate management structures as hallmarks of the approach (Gyapong et al., 2010). Although control measures are instituted and maintained in a long-term perspective, activities are time-limited, often intensive, targeted, and organised in circumscribed programmes (Melgaard et al., 1998). For many donors and political establishments, vertical programmes are attractive because they give quick results and are easier to manage than horizontal, integrated programmes (Atun et al., 2010). However, the approach has been criticised as it can divert human and financial resources from already resource-constrained systems and is detrimental to overall health systems development (Msuya, 2004).

Since adopting a selective approach to public health, donor-designed packages, called vertical programmes, were hailed as the preferred way to the success of public health in developing nations. Historically, vertical programmes were seen as a pragmatic solution to fund health programmes rather than adopting the more difficult and expensive WHO comprehensive PHC (Cairncross, Periès and Cutts, 1997; Ortiz, 2007). For running these programmes, public health infrastructure, funds, and workforce were required which developing countries lacked. After ratifying the Alma-Ata declaration, these countries had no choice but to support the vertical programmes despite having inadequate infrastructure and workforce as it was a condition of receiving donor funds (Haines, Horton and Bhutta, 2008; WHO, 1978). As India experienced a sizeable fiscal deficit in 1991, health reforms of that time were a forced action by the government to respond to this economic crisis (Dayal, 2014).

Additionally, a severe fiscal crisis triggered by global events like the collapse of the Soviet Union, unpaid foreign debts, and the Gulf War, resulted in a large fiscal deficit, sharp currency devaluation, and a low credit rating for India by the global market (Corbridge and Harriss, 2013). As the conditions worsened for the United States, the World Bank and International Monetary Fund (IMF) stopped their assistance to developing nations, leaving the Indian government with no other option but to pledge its gold reserves to the IMF in exchange for a loan to cover its debts (Corbridge and Harriss, 2013). The crisis led to mandatory structural reform under the conditions stipulated by the World Bank, which became known as economic liberalisation (Mattoo and Stern, 2003). The crisis led to strict conditions for the government to seek funding from international donors (Corbridge and Harriss, 2013). The resultant policies altered India’s traditional centrally planned policy development process into a donor-dominated process, which impacted the public health system (Corbridge and Harriss, 2013; Mattoo and Stern, 2003

3.7.1. Vertical Public Health and the Indian HIV Counselling Programme

> *Coordinated by UNAIDS, and guided by the UN Country Team, the Joint UN Team on AIDS in India brings together different UN agencies and UNAIDS co-sponsors to support the government, civil society, and community efforts.*
>
> *United Nations (n.d.)*

After ratifying the Alma-Ata declaration (1978), India supported a vertical approach to the HIV programme, relying on UNAIDS for funding (Carlson, Druce and Sadanandan, 2004). The NACP in India has received funding from UNAIDS since its first phase in 1992 (NACO, 2011), supporting its inadequate infrastructure and workforce. India, being an endorsee to the Millennium Development Goals in 2000 (United Nations Economic and Social Commission for Asia and the Pacific, 2015) and a signatory to the declaration of commitment to HIV/AIDS in 2001, has adhered to guidelines by UNAIDS for its execution. Given the massive reliance on foreign funds in the initial stages, the Indian government was compelled to change its strategies to match UNAIDS and the Global Fund’s concerns for HIV interventions (Kates and Lief, 2006). The following section presents a chronological discourse on the verticality that shaped the Indian HIV programme and how it relates to the issue of effectiveness. The above excerpt from the United Nations website on HIV/AIDS programme in India, and similar claims on the NACP website, position the programme as a globally acclaimed success story. However, several challenges were faced with financing the programme and keeping it sustainable and appropriate for the Indian community.

Though vertical programmes had their failings, they were preferred by donors who refused to fund comprehensive public health due to their higher costs and inability to control resources (Atun, Benette and Duran, 2008). Some of the vertical programmes have shown progress in delivering effective public health in developing nations with success in the fight against certain diseases. STOP Polio, UNICEF’s child vaccination programme (Alonge, 2020; United Nations Children's Fund, 2018), and the programmes on vector-borne diseases with similar delivery strategies and interventions, such as onchocerciasis, lymphatic filariasis, and soil-transmitted helminthiasis, are some examples of successful vertical programmes (Gyapong et al., 2010).

However, the critical reasons for the success of these programmes were that the diseases they were addressing were treatable, and, once treated, the clients did not require preventive treatments (Gyapong et al., 2010). For HIV, and other programmes dealing with complex and long-term conditions, prevention and treatment are required for both existing and new clients. This requires more funding which makes them less sustainable. The programme has also been insufficient in achieving desired outcomes within prescribed periods, further impacting donor funding (Gyapong et al., 2010).

This need for funding and inability to achieve desired outcomes led to an endless cycle where the recipient nations became dependent on external funding to cater to greater programme demands and more staff salaries, while still hoping to get even more funds. The mismatch between demand and supply led to an interruption of the flow of funds, making it harder to achieve the prescribed targets within the deadlines. Researchers argue that targets set by donor agencies have been unachievable for HIV programmes run in resource-limited nations like India (Vemula, 2011; Watney, 2013).

For HIV/AIDS, the vertical programme was named the Joint United Nations Programme on HIV/AIDS (UNAIDS), co-sponsored by various United Nation bodies like World Bank, Global Fund, and the WHO (UNAIDS, 2009a). Since 1994, UNAIDS has been the leading advocate for accelerated, comprehensive, and coordinated global action on HIV/AIDS pandemic globally, including in India. UNAIDS followed the WHO’s Global Programme on AIDS (GPA) 1987, with the objectives of preventing transmission of HIV; reducing the personal and social impact of HIV infection and AIDS on those already infected, their friends and families, and communities; and coordinating national and international efforts against AIDS (WHO, 1989). Its six programme objectives were centred on providing global leadership in response to the epidemic, promoting global consensus on HIV prevention and control policy, and strengthening the capacity of governments of member nations to develop and implement effective HIV/AIDS programmes.

Since the ratification of India to the cause, UNAIDS has been the largest funder for the Indian HIV/AIDS programme, with the funding later continued by the Global Fund. Though UNAIDS was seen as improving the quality of HIV services by providing focused technical assistance for HIV prevention and control, it was criticised by media, social scientists, and its own ex-directors (France, 2006; UNAIDS, 2009a), due to its smaller contributions to HIV programmes (UNAIDS, 2009a). In India, with its competent workforce with skills in psychology, HIV prevention and treatment, UNAIDS's role was limited to advisory, providing technical assistance to the HIV programme (UNAIDS, 2009a). Arguably, while UNAIDS' information and technical support were valued, it was not considered an effective coordinator of HIV services in developing nations.

The UNAIDS (2009) has been criticised for being too process-oriented and as an agent that lacks focus on deliverables. Reportedly, UNAIDS had also been known to hastily move headfirst toward newer goals while missing opportunities for genuine evaluation of the earlier goals (France, 2006). Such missed opportunities prevailed in several global HIV-related programmes run by UNAIDS in developing nations like India (Vemula, 2011) and Africa (Warren et al., 2017). As the agency was not politically committed, had limited financial resources, and missed opportunities for collaborations, it was unable to strengthen the linkages between the programme and the national health system. Further, the Indian government prioritised infrastructure development over having a sustainable public health system, which again restricted the financial support to the programme (Vemula, 2011)

To address UNAIDS’ challenges, the Global Fund was established in 2002. Since the advent of the Global Fund, UNAIDS is no longer a player in resource mobilisation or agenda setting. The Global Fund is a public-private partnership (Swiss Agency for Development and Cooperation [SDC], 2017). Headquartered in Geneva, among other United Nation offices, the Global Fund's operations are mainly controlled by United Nation policies. It receives contributions from bilateral donors and private foundations like the Bill and Melinda Gates Foundation (BMGF) (Hood, 2011). The Global Fund gradually took over the funding responsibilities of UNAIDS and was the most prominent international financer to attract, leverage, and invest resources for HIV/AIDS, tuberculosis and malaria prevention, treatment, and care programmes (Gharib, 2016; Global Fund, 2017) in several developing countries. Based on the 2002-2008 UNAIDS evaluation report, UNAIDS has been criticised for being slow to respond to the changing environment and missing the opportunity to become the technical arm of the Global Fund (2009). The Global Fund had to establish a parallel technical support system for its day-to-day operations. As of July 2018, the Global Fund (2018) had disbursed more than USD 40.3 billion to support these programmes.

Based on the review of the Global Fund operations, it can be inferred that the Global Fund is more of a financing mechanism rather than an implementing agency. The HIV programmes funded by the Global Fund are implemented by in-country partners like the Indian Ministry of Health, while the Global Fund Secretariat monitors the programme (Global Fund, 2009). A tripartite structure was adopted by the in-country partners where the Global Fund acts as a funder, UNAIDS as a technical advisor, and the local country coordinating mechanisms as the coordinators (Global

Fund, 2009). The idea was to enable a faster, more transparent, and less bureaucratic system, with accountability for results and broader public health benefits (Global Fund, 2009). Arguably, the Indian government also prioritised mainstream public health funding while less funding was devoted to HIV.

Interestingly, the Global Fund was criticised by its technical review panels for not clearly understanding recipient nations' health systems (Global Fund, 2008; Warren et al., 2017). Vertical programmes failed to strengthen the Indian public health system or address its diversities (Weber, 2011). The Global Fund's disease-specific grant proposals had a clear action plan; however, its proposals for strengthening health systems were vague. The agency lacked a clear understanding of strengthening the Indian public health systems and responding to its constraints (Global Fund, 2008). Though the past few decades have seen increased advocacy for vertical programmes for several reasons, questions remained on their long-term sustainability in terms of outcomes and resources. As programmes moved ahead, the Global Fund also faced a higher demand for funding from India and other developing nations, which it could not fulfil. This mismatch between demand and supply interrupted the flow of funds, making it harder to achieve prescribed targets within deadlines.

Measurements of programme effectiveness have shifted from being health-centric to business-centric, depicting a neoliberal model of public health that focuses on achieving cost efficiency (Tulchinsky and Varavikova, 2014). The achievements of the HIV programme were measured in terms of commodified redistribution of funds and not based on preventive or behavioural change aspects. The quality of counselling services was measured in numerical inputs and outputs. The number of condoms distributed was used as the indicator of prevention from sexual transmission of HIV in NACO's recent report (NACO, 2018b). The number of sterile needles and syringes distributed was used as an indicator of the prevention of HIV transmission through injectable drug use (NACO, 2018b). The number of certified personnel was used to indicate the quality of HIV counselling services (NACO, 2018b).

Similarly, the number of clients tested for HIV was used as an indicator of adherence to the risk-reduction strategy (CDC, 2016). These indicators derived from the programme implementation model are reported in annual reports (CDC, 2016) and indicate that the process of measuring programme effectiveness and performance ignored the aspects of behaviour change. This is to say that the funders lack an understanding of the countries' local context. Although they were competent at managing finances, they lacked the local knowledge to develop the HIV programme. Funders never engaged with the country-level coordinators but forced the local staff to coordinate HIV prevention and control operations by themselves (Warren et al., 2017). The overall financing system for health is profoundly misaligned. The vast majority of health spending is spent on treating disease, and an inadequate proportion is provided, ineffectively, to support public health efforts showing that the nation is not spending on what is needed to produce the health outcomes it seeks (International Organisation for Migration [IOM], 2012).

In parallel, in the early 21st century, the Indian government practised financial capping on its health budget, limiting domestic funding to its states. The PHPs were largely reliant on international donors (Kapur, 2015; Sadanandan and Druce, 2004) and received funds based on the attainment of their performance goals. Those PHPs that were unable to achieve these goals were categorised as underperforming and received reduced financial support (Kruk et al., 2018; Roa, 2019). Several states had to resort to NGOs, like the Gates Foundation, funding their PHPs. Avahan Project (2003–2009) was an example of HIV/STI prevention activities funded and coordinated by the Gates Foundation in six Indian states (BMGF, 2009). This funding process circumvented the fiscal limits imposed by the government budget, undermining its financial accountability. The most significant reduction of funds happened during the second phase of the HIV programme (1999-2004) when many states sought help from NGOs (Sadanandan and Druce, 2004).

Despite a significant decrease in development aid provided by World Bank from 1990 to 2000, a shift in funding systems was observed. A plethora of new health agencies and initiatives emerged after 2000, aiming to improve health outcomes in developing countries (Weber, 2011). The financial assistance for health given by new global health agencies and initiatives grew four times to a staggering USD 20 billion by 2007 (Ravishankar et al., 2009), as compared to the amount spent in 1990, which increased to USD 40 billion by 2018 (Global Fund, 2018). Global Fund and bilateral non-governmental organisations (NGOs), like the BMGF, became a channel for redistribution of this increasing share to HIV programmes (Global Fund, 2018; Ravishankar et al., 2009). Much of this increase was focused on medicines, commodities, and technologies, and fewer funds were directed towards behavioural change and health systems support (Global Fund, 2018; Ravishankar et al., 2009; Weber, 2011).

As the contributions from NGOs, foundations, and the private sector increased, they demanded higher engagement in the governance mechanisms of the Global Fund (2009). The model raised concerns as several stakeholders of the country coordinators received money from the Global Fund, either as grant recipients, sub-recipients, private persons, or contractors. For instance, India HIV/AIDS Alliance (IHAI), a south Indian NGO, received funds from the Gates Foundation for HIV/STI prevention as a part of the Avahan Project. As of 2009, the Gates Foundation had pledged USD 338 million to six Indian states for this project (BMGF, 2009).

3.8. Aspects of Programme Implementation in Post-colonial Era

As discussed earlier, the Indian government could not fund the programme, which became dependent on external funding to cater to its demands and staff salaries. The funding was insufficient to provide the minimal infrastructure and workforce needed for its implementation. Besides the donor hegemony, bureaucratic delays and high corruption led the government to be unsuccessful in developing a publicly funded health system. The programme has been under-resourced and faced problems concerning its poor design and implementation. As discussed, effectiveness measures ignore the qualitative aspects, social impacts, and associated stigma (Vemula, 2011). With the epidemic rapidly expanding and the state governments juggling other important affairs, the state missed the opportunity to develop their infrastructure and workforce for HIV control, hoping they would get more funds to do so and creating an endless loop of borrowing.

In India, HIV/AIDS was referred to as a “western disease” (Llewellyn, 1994) and “a disease of the poor, the illiterate, the prostitutes and the deviants” (Fineman, 1990). These phrases depict the opposing views of late 20th-century researchers towards HIV with a strong sense of denial of the actual threat of the disease. The presumption was that HIV was restricted to a deviant section of society and not a threat to the general populace. This presumption coincides with the current definition of HIV as a concentrated epidemic.

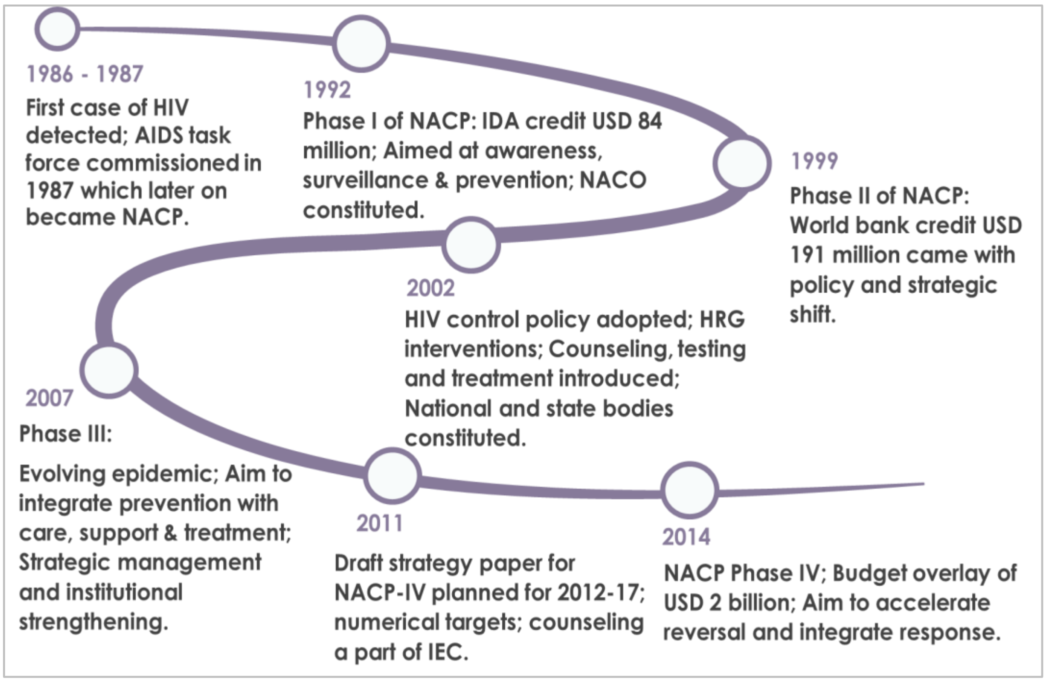
India has a quasi-federal government where the provision of health is the state’s responsibility, which is the provincial government. States with a higher prevalence of HIV were unable to fund their HIV control activities (Pisani, 2010). The unchecked spread of HIV resulted in further higher indirect costs, like orphaning, social stigma, suicides, and professional burnout that were damaging their already heavily burdened societies; thus, making the public funding for the programme more unsustainable (Mukherjee et al., 2003).

The Indian government also showed a strong denial of the actual threat posed by HIV/AIDS, blaming the rise of infection on the increasing influx of foreigners. As a response to the first cases in 1986, legislative formulation and policy and institutional arrangements were enacted, including a quarantine law for HIV/AIDS cases, a mandatory HIV test for international students, recommending the prohibition of sex with non-Indian residents, mostly tourists (Asthana and Oostvogels, 2001), and those tourists who were tested positive were deported to their home countries (Xinhua, 1988). The government wanted to bring this programme to an end in the early 1990s because of limited budget allocations. Moreover, malaria was a bigger priority for the government, taking up half of the national health budget (Jayaraman, 1986).

Since the first few cases of HIV/AIDS were reported in 1986 amongst FSWs of Chennai and Mumbai, two prominent Indian metropolitan cities, the epidemic was thought to be concentrated among HRGs (Jayaraman, 1986). A year after the first case, the AIDS task force was commissioned to analyse the spread (Figure 3.1) (Ramachandran, 2012), which found that three-quarters of infected people lived in prominent south Indian cities (Ghosh, 2002), with a higher number of FSWs and IDUs reported in north-eastern states (ISHA, 2004). Contrary to these claims, the HIV epidemic was not geographically restricted. By the 1990s, all Indian states had reported HIV/AIDS-infected cases (UNGASS, 2008), including Himachal Pradesh.

Figure 3.1

Historical Timeline of NACP Adopted from NACO (2011, 2016)



In 1992, India received its first aid from World Bank as an International Developmental Agency (IDA) credit of USD 84 million to launch the first phase of NACP to set up a surveillance system and ensure access to preventive services HRGs (NACO, 2006b). The second phase introduced HSS, which significantly changed the estimated number of HIV/AIDS-infected people, and later affected the programme design (NACO, 2009). The HSS in India was conducted in 2006, and its results were published in 2008 (NACO, 2008). This activity calculated HIV prevalence separately for three categories: (i) HIV positivity rates among antenatal clinic (ANC) attendees representing the prevalence in the general population; (ii) MSM, HTG, FSWs and IDUs, which were collectively categorised as HRGs; and (iii) population groups likely to act as a bridge for HIV transmission from HRGs to the general population through unprotected sex or unsafe injecting drug use (e.g., SMM, LDTs, including patients attending sexually transmitted infections (STI) clinics) (NACO, 2008).

As surveillance activities expanded, the number of infected people became higher. In 1999, the number of PLHIVs reached 3.7 million (Khan and Bano, 2008). In response to this increase, the second phase of NACP was launched in 1999, with an additional aid of USD 191 million from the World Bank (NACO, 2006b). For this reason, the programme experienced a strategic shift with a newer aim of reducing the spread and increasing national capacity for a long-term response. As an outcome of this shift, the following programmes were introduced: HIV counselling and testing programme; targeted intervention programmes for HRGs; and HIV treatment programme. For HRGs, it functioned as the key point of access for HIV diagnosis and treatment. Due to expanded activities in phase II, the number of PLHIVs reached 5.1 million in 2005, a staggering increase of 40% compared to 1999 (Khan and Bano, 2008).

In 2006, a top-down structure was developed to manage the programme, with the Prime Minister chairing the National Council on AIDS, which was on top of the organisational hierarchy, NACO being the centre, and state AIDS Control Societies (SACS) as state bodies at the grassroots level (NACO, 2006b). However, a non-integrated, donor-dependent approach to HIV control in India presented its share of challenges.

By 2006, the total number of HSS sites increased to 1,122 compared to 180 at the start of NACP phase II, aiming to cover all the country’s districts. Sixty percent of the surveillance sites were established at ANCs, where mandatory HIV testing was done for pregnant women. Forty percent of sites were established at STD clinics, de-addiction centres, drop-in centres (DIC), and other service points to test HRGs (NACO, 2006a). Sampling was done annually or until the end of the 3 months until the following samples sizes were achieved for each site, which was 400 ANC, 100 OBG (Obstetrics and Gynaecology), 100 STD clinics, and 250 from other HRG sites (NACO, 2008).

The national HSS 2006 results showed that 5% of HRGs had HIV/AIDS; for ANC, the percentage was less than 1 (NACO, 2008). Although the state-wide trends were quite similar to the earlier phase of NACP, with higher rates in southern and north-eastern states, several northern states like New Delhi, Chandigarh, and Punjab also joined the list of high HIV prevalence for HRGs, especially for MSM and IDUs (NACO, 2008). The importance lies in the fact that these states share geographical closeness with the Una district of Himachal Pradesh.

Surprisingly, apart from the bridge population, HSS 2006 did not separately measure HIV prevalence in HTGs. There is no clear indication of whether they were counted with the other HRGs or excluded from the surveillance. More recent statistics reported that the HIV prevalence of HTG was higher than the other HRGs, but due to their smaller number, HTG lacked targeted intervention until phase III of the programme (NACO, 2013).

Himachal Pradesh has had conflicting reports of its HIV trends since its initial HIV surveillance activities. HSS 2006 indicated that the state had 0.4% MSM suffering from HIV, which reached zero in HSS 2007 (NACO, 2007c). Although neighbouring states had a high prevalence of HIV in HRGs, Himachal Pradesh had no surveillance sites to count HIV prevalence in IDUs or HTG before Phase III of the programme. Therefore, no credible data on HIV prevalence for these groups are available for the initial two phases of the programme.

Although under-researched, the use of proxy prevalence indicators to estimate the HIV rates for the general population by HSS 2006 resulted in the figures significantly lesser than the ones released in earlier years. The estimates from the general population and results of HRG-targeted surveillance brought out a new count for PLHIVs in India, amounting to 2.5 million and a prevalence of 0.4%, which varied between 0.45% in 2002 and 0.36% in 2006. Other than the HIV testing and surveillance results, this estimate also encompassed results from three other national surveys—National Family Health Survey (NFHS-III), Behavioural Surveillance Survey (BSS-II), and IBBA survey.

Lakashe et al. (2008), in an epidemiological study of HIV infection in India, reported that this new method was also used to "back-calculate" HIV/AIDS prevalence between 2002 and 2006. This method was based on a new set of assumptions and measures to allow a fair comparison of year-on-year trends in HIV prevalence; that is, "comparing apples with apples". The finding showed that the epidemic was stable over time, with a marginal decline in 2006 and a significantly lower figure than the 2005 estimates of 5.1 million. However, even though the 2006 report made the Indian political leaders comfortable with a lesser disease burden, it also gave a dire forecast. The report stated that 11 million people would die from AIDS in the next 20 years if no effective measures to combat the disease were implemented (Raghuraman, 2006). This alerted the government to move towards the third phase, which was launched in July 2007. Its goal was "Halting and Reversing the Epidemic" by the end of the project period.

As noted in the previous sections, the vertical NACP programme has failed to deliver effective public health to the Indian HRGs. Like most vertical programmes on HIV in developing nations, NACP lacked community engagement for its development and execution. The donors focussed more on HIV treatment (UNAIDS, 2013b), condom distribution, and safe needle syringe supply, but were ineffective in addressing basic community needs.

3.9. Summary

With this critical review, I have analysed the more significant policy problem, which is a non-integrated model that largely relies on foreign funds, the evolution of a vertical HIV control programme in India, the gap between HIV policy and its practice, and the non-engagement of local players in programme design. This analysis was considered against the historical backdrop of the disease control measures during colonial times and the decline of the ancient indigenous Indian health model, overtaken by allopathic influences. This decline is considered a significant missed opportunity as Ayurveda and locally strengthened public health has much to contribute to a public health response.

The HIV epidemic is not merely a public health problem for India; it has impacted the country's economic growth (Oja and Pradhan, 2006). The first case of HIV in India was identified in 1986, a few years before the country faced a sizeable economic crisis that consequently resulted in economic reforms. A blanket approach was adopted to the Indian HIV epidemic to address the challenge of serving the large Indian population, which may have benefitted other infectious disease programmes but failed to serve the purpose of HIV due to the concentrated nature of this epidemic. The ambition of economic development in a resource constraint environment forced the Indian government to spend less from public funds and primarily rely on donor funding for such public health issues. However, due to the disrupted flow of funds and receding donor funding, the public health system was left with no other option but to operate with limited resources delivering services that were not effective in controlling the epidemic.

This disease has hampered India's economic development (Yuk-ping Lo, 2015) and has been a severe socio-economic and developmental issue for India (World Bank, 2012). The Indian Ministry of Health plans to fully fund its vertical PHP, including the HIV control programme, and integrate it within the comprehensive public health service called the National Health Mission (NHM) (Patel, 2014). A better model of funding with more domestic partners/advisors involved at all stages would have been beneficial to increasing the effectiveness of HIV programmes. As a step towards such self-reliance on funding, India needs to bring programmatic changes by improving its foundational capacities, providing flexibility at a local level (IOM, 2012), and enabling increased citizen ownership in deciding its effectiveness (Haldane et al., 2019). The programme’s integration within the existing system (NACO, 2014) is essential to ensure its long-term sustainability and support its resilience (Witter et al., 2019). These are the critical early steps for living up to UNAIDS’ (2010) fundamental mission of “universal access to HIV prevention, treatment, care and support”.

CHAPTER IV – RESEARCH DESIGN

An AI to improve the HIV counselling programme in Una district, Himachal Pradesh State

> *More, I attempt to investigate my research through a subjective lens; more pulled am I to discuss who we are and how we think of our lives.*
>
> B. Nair's journal entry (4.1)

4.1. Introduction

This chapter outlines the methodology, ethics, location, and participant recruitment, data collection and analysis processes. It begins with a discussion of my positionality for this thesis, describing how I made the choices for appropriate research design in relation to my experiences and vis-a-vis the counsellors and clients and their social context, and how that affected methodology. This is followed by a discussion about the choice of a theoretical framework and research methodology. The chapter also gives a first-hand experience of encounters and surprises in the field, and the careful and constant negotiations that were part of the research process.

As discussed in earlier chapters, this study aimed to explore the effectiveness of HIV counselling in Una district, Himachal Pradesh state, northern India, from the perspectives of key clients, the HRGs of Una district, and FCS. The main research question asked was: “How can the HIV counselling programme delivered in Una district, Himachal Pradesh state, Northern India, be made more effective?”. The three sub-questions that relate to the above research question are:

1. How has the Indian HIV counselling programme evolved and how has that shaped programme effectiveness today?
2. What are the views of FCS and HRGs on HIV counselling programme effectiveness?

3. What strategies might evolve from the perspectives of FCS and HRGs and how could such strategies improve the effectiveness of HIV counselling programme?

The first sub-question considers current knowledge about the evolution of the Indian HIV programme and how that has shaped effectiveness today. Sub-questions two and three, are the empirical part of the study, focused on engagement with the CRs to explore the effectiveness of the HIV counselling programme from their perspective.

4.2. Research Positionality in Relation to the Methods

In the beginning, I struggled to develop an appropriate approach for choosing a study design that could adequately capture the viewpoints of FCS and their high-risk clients, utilise their capacities, and tell their stories as a part of the programme. The following section tells the story of how I chose AI as the research methodology.

Previous training in biomedicine had given me a positivist perspective of cause and effect, believing truth as objective and generalised (Henn et al., 2009). The fundamental idea behind biomedicine is that the practice of medical diagnosis and intervention should be guided by systematic biomedical research (Martini, 2020). I assumed that the vast knowledge the world has gained through advances in biomedicine, evidence-based medicine, diagnostics and treatment that followed a positivist paradigm, were sole methods for discovering truth (Masic, Miokovic and Muhamedagic, 2008). In contrast, I assumed that other systems were ‘unscientific’ (Shang et al., 2005), accepting the prevalent conflicting evidence (Rutten et al., 2013). However, this has not always been the case; historically, biomedicine was considered an art with principles and techniques based on experience (Martini, 2020) and “guided by millennia of common sense” (Goldman and Schafer, 2012, p. 1). Personal knowledge and experience were believed to have a primary role in the development of biomedicine (Martini, 2020).

After coming to AUT, I devoted the first year of my PhD to understanding qualitative research and common theoretical frameworks employed in this research process in New Zealand and abroad, given that this seemed to be a means to provide an opportunity for research participants' voices to be central to the process. I was always passionate about working for FCS and HRGs. Before joining doctoral studies, I was associated with the Indian HIV counselling programme as a trainer to counsellors and other FCS. During this training, I learnt the programme's qualitative aspects from the counsellors' perspectives, which were usually ignored in a quantitative progress report. These reports assumed that effectiveness solely relied on quantitative variables encapsulated within predefined boundaries, while epistemologically qualitative research explored beyond the pre-imagined boundaries of the research problem (Crotty, 1998). I learnt that the counsellor's perspectives were not encapsulated within boundaries but varied with changing context, geography, social determinants, and other factors. However, I was ignorant of ways to gather, analyse, and interpret such data, and about the foundations of epistemology relating to such methods.

On further exploration of research methods, I understood that a theoretical framework for a qualitative research approach can facilitate understanding concepts and variables that give definitions and build new knowledge while validating them (Ravitch and Riggan, 2016). This approach cannot apply a quantitative validation method as it focuses on the consistency of procedure and the capacity to generalise the outputs to other contexts (Whittemore, Chase, and Mandle, 2001).

Initially, I struggled with subjective concepts, finding them fuzzy, vague, and non-structured. However, the more I researched the purpose and processes of qualitative research, the more I appreciated what philosophers, spiritual leaders, ancient wisdom, and researchers from other paradigms have always known—there is more than one construct of reality (Egan, 2018). I learnt that quantitative methods have always been the "gold standard" of research, and these "government-sanctioned, exclusivist assertions of positivism" (Wright, 2006, pp. 799-800) have constantly threatened the very existence of qualitative research (Wright, 2006). The "one shoe fits all" (Denzin and Lincoln, 2010) approach of quantitative research ignored the value of qualitative enquiry in addressing matters of equity and social justice (Denzin and Lincoln, 2010). As discussed in Chapter 3, it is recognised that qualitative research produces vital knowledge that focuses on values and power relevant to ordinary citizens and policymakers (Eisenhart, 2006; Flyvbjerg, 2012). Ignorance of these realities by the policy maker, government, and donors urged me to explore, interpret, debate, and critique the social realities from an inclusivist qualitative research perspective.

Early in my doctoral studies, I attended a presentation on AI, a process improvement approach exploring what gives life to the organisation and its members when they are at their best (Cooperrider and Whitney, 2007). This presentation attempted to discover what worked well within an existing healthcare service and to replicate those approaches. This fascinating methodology argued that a change that focused on what people do well was more engaging and motivating and more likely to be sustained than focusing on what is going wrong (Watkins and Mohr, 2001). The findings in Chapters 5 and 6 indicate that positive approaches could improve structural and social factors impacting HIV counselling programme, and for that, HRGs need to be engaged in programme design and delivery. Critical discussions with an AI researcher (Mace et al., 2014) and several readings on AI indicated a growing body of AI research in health and social care (Carter, 2006). These searches referred to AI as a philosophical guide, a research lens, or an appreciative eye. These exercises and experiences allowed me the progress my understanding of AI and helped create an appropriate study design for the research.

Cooperrider's thesis on AI was mentored by Professor Suresh Srivastava, an Indian researcher (Taos Institute, 2022). The Indian philosophical concepts of *advaita* (non-duality), *lok-sangrah* (inclusive, systemic endeavour), *sattvic* (pure), *karmic* (endeavour), and *sankalpa* (intention) have been discussed in conjunction with AI to transform human connections and transcend sociocultural differences (Pandey, 2013). These concepts have a generative connection that led to AI's co-creation and development (Verma, Waturuocha and Fry, 2013). AI has been employed to reinforce the strengths of Indian communities through developmental projects for facilitating sustainable livelihoods (Ashford and Patkar, 2001) and in improving health care practices for various infectious diseases (Merriel et al., 2022).

Following these learnings and experiences, AI appeared as the most appropriate research method for exploring what had worked well in HIV prevention and counselling programmes in Una and how that can be replicated in future. One example of knowledge that AI can help to elicit is how an effective and harmonious counselling session can bring the most significant sustainable change in clients, encouraging them to bring more clients to that counselling centre. In 2015, I presented the field study design for this thesis at an HIV symposium, where I received advice and critique from HIV researchers from various universities. The presentation was later published as a chapter in symposium proceedings (Nair, 2015). The following sections discuss the theoretical framework and methodology used to give voice to FCS and clients in relation to the programme.

4.3. Critical Theory and the Voices of CRs

After positioning myself in the study, this section discusses the theoretical framework that was applied to elicit the voices of CRs; that is, the FCS and HRG clients in the programme in Una. In this research, a critical theory framework informed the methodology as its basic tenet is the importance of empowerment and elicitation of voices of the vulnerable and voiceless. Critical theory is well recognised as considering and calling attention to voices of marginalised groups on sensitive issues—voicelessness because of years of colonialism where being suppressed was normal. This Indian experience was followed by donor domination of the HIV programme. The people associated with the disease and its risk factors were left dependent on external funds for their testing and treatment.

A critical perspective was also considered appropriate for evaluating the effect of India's pre- and post-colonial and neoliberal experiences of the programme. A critical theory is often used to analyse the impact of colonialism, focusing on its consequences of control and exploitation on colonised people and their countries (Sarangi, 2010). The colonial impacts on government systems exhibit historical inequalities and power dynamics, resulting in a situation of oppression among the people (McKinley, 2014.; Sawant, 2012). The dependency of the HIV programme on external aids makes this framework the most suitable for evaluating it (Baum, 2016), while tracing India's evolution from a British colony to an independent republic.

Critical theory is inherited from Marxist philosophy and has many variants (Crotty, 2013). Horkheimer defined critical theory as a social process oriented toward critiquing and changing society characterised by exploitation and contrasting power relations (Held, 1980). Grant and Humphries (2006) stated their appreciation for critical theorists like Derrida, Foucault, and Lyotard to facilitate change and promote human potential, not limited to critiquing social realities. These philosophers argued that assumed organisational power and power differences perpetuate using negative language, often presenting an issue rather than a solution. Mace et al. (2014) also presented the discourse as an issue rather than a solution that challenges research beyond human rights and de-stigmatisation. These researchers explore the issues of health care accessibility faced by marginalised communities in a resource constraint environment.

HIV programmes have primarily ignored FCSs' and HRGs' perspectives on cultural acceptance (Farmer, 1999), confidentiality, and discriminatory behaviour (Scambler and Paoli, 2008). Moreover, these people feel pressure from their families, experience financial difficulties (Farmer, 1999), social stigma, and marginalisation (Scambler and Paoli, 2008). In various cases, the views of clients have not been taken into consideration for developing future health policies and programmes (GoI, 2014); nor in their planning and evaluation (Ahsan, 2008; GoI, 2014; Halli et al., 2007; United Nations Research Institute for Social Development [UNRISD], 2015). A critical approach is vital for exploring these issues.

In its emancipatory aims, critical theory envisions a society fostering freedom and meeting the needs of every member (Baum, 2016). It promotes a state of inclusiveness and honour for CRs. It opens doors to in-depth dialogues about gender, sexual orientation, race, age, culture, and religion (McArthur-Blair and Cockell, 2012). In the context of public health practice, a critical approach explores the agenda of change in social reality, especially the realities of the vulnerable who suffer significantly from ill-health and risk.

As discussed in Chapters 1 and 2, the lack of effective HIV counselling services has been a significant issue in India. The perspectives of HRGs and FCS, the CRs of this study, are a crucial contribution to its improvement. Despite that, the CRs' stories are seldom given importance in policy development. The programme planners rarely invite these groups to design the programme or make proposals as they are considered at the bottom of NACP’s hierarchical pyramid. They remain voiceless and marginalised in HIV policy development.

Thus, for this study, critical theory emerged as the most suitable research framework to improve the programme as it uses inquiry methods appropriate for researching a world characterised by domination and disparity (Clark, 2002). Here, it is supported by a methodological space where the voices of these groups can be elicited. It acts both as an essential philosophical idea and a reflective process to enable the CRs to voice their experiences and suggest change strategies (Grant and Humphries, 2006; Reed, 2007). Critical theory has been identified as the best theoretical perspective to create space to such disadvantaged people for sharing perspectives, especially when researching vulnerabilities and sensitive issues. It shapes a mutual learning process that helps share decision-making power with the CRs (Clark, 2002).

In the context of programme improvement, this method will help create space for FCS and HRGs to question the social order and allow their perspectives to be at the forefront of the research (Fay, 1993). As a participatory research methodology, AI created the platform for marginalised and disadvantaged groups to share their perspectives on sensitive issues of quality, accessibility, and privacy in HIV counselling (Cahill, 2007; Cornwall and Jewkes, 1995).

4.4. Participatory Research: Methodology Underpinning the Research

> *Participation has been a central tenet of improving health since the World Health Organization (WHO) released its Health for All campaign. It has been a means to overcome public health professionals’ dominance, improve strategies both in practice and research, and show a commitment to democratic principles.*
>
> Baum et al (2006)

Participatory research has historical roots in Lewin’s work on collaborative methodologies and Freire’s education movement (Minkler and Wallerstein, 2011). Lewin rejected the positivist belief of an objective world of research separate from the subjective meanings understood by its people and their actions (Peters and Robinson, 1984). By the 1960s, participatory research emerged as an action paradigm that challenged the positivist worldview and explored the importance of participation, addressing power relations in the research process to create a just and more equitable society (Kindon, Pain and Kesby, 2007; Wallerstein and Duran, 2003). Participatory research focuses on gaining knowledge through participation, emphasising locally defined priorities and perspectives (Cornwall and Jewkes, 1995). It links critical theory and its practice, thus recognising power-sharing and collaboration between researchers and research participants, referred to in participatory research as CRs (Grant and Giddings, 2002).

Participatory research has been implemented in developing nations through various methods such as rapid assessment procedures, rapid rural appraisal, and participatory rural appraisal (De Koning and Martin, 1996). As an emancipatory research approach, participatory research has roots in Freirean neo-Marxist approaches to community development (in Latin America) as well as human rights activism (in Asia) (Fahy, 2015). Its focus on critical community voices in PHP development (Almond, Cummings and Turner, 2015) has widely influenced international health systems research (Oetzel et al., 2015). In comparison, the politics of conventional social research may serve only the wealthy and powerful as their voices inform the public policies (Denzin and Lincoln, 2002). Given its commitment to the social, economic, and political development of non-elites, participatory research is often associated with liberation and social transformation.

Participatory research aims to integrate the methodological intentions of critical theory for the systematic collection and analysis of data for bringing change (Gillis and Jackson, 2002). This is a crucial aim of the current research as it draws out solutions based on intellectually and morally rich traditions, ideas, and challenges shared by the coresearchers (Kemmis and McTaggart, 2005). The shared ownership of research, community-based analysis of social problems, and an orientation towards community action make it different from other conventional research approaches (Kemmis and McTaggart, 2005). It is necessary to enable marginalised communities to express their voices, but it is insufficient to solve their health needs. Policymakers need to engage in an active dialogue with these communities on how to solve their health issues (Rodriguez and Brown, 2009).

In this research, participatory research emphasises the value of mutual social learning during and after the investigation process (Gaventa and Cornwall, 2006). Although with a particular focus on participation, participatory research has not been without its critics who have indicated a mismatch between participatory research theory and the practice of participation (Cooke and Kothari, 2001). Although participatory research finds its origins in Lewin’s social action research from the 1940s, it primarily draws on Freirean work on education-promoting community leadership from the 1970s (Macaulay, 2016). The criticism of participatory research dates back to the late 20th century when Couto (1987) argued that it was challenging to achieve participation by an external professional researcher from outside the community. Although participatory research unmasks people’s truth by validating people’s knowledge (Hall, 1975), its researchers involve non-researchers with limited training to practice participatory research principles (Couto, 1987). This could compromise the validity of local knowledge if the practice of participatory research impacted the discourse. Mosse (2001) strongly advised avoiding participatory research in agency-funded research because agencies can manipulate participant responses to pursue their agendas. However, Francis (2001) gave a broader solution to the problem highlighted by Mosse (2001). He advised that an agency-funded project should value the structural dimensions of social relations. They should substantially include the voices of beneficiaries in project implementation to incorporate participation. Likewise, Kesby (2007) emphasised the importance of structural dimensions, stating that over-emphasised focus on local experiences loses sight of interactions between broader structural processes.

To summarise, the new knowledge could impact how the participating non-researchers identify them in discourses. CRs may not identify power as a critical factor of their marginalisation (Cahill, 2007) but may expand their knowledge of their social roles. Despite these important critiques, participatory research represents a viable, vital alternative to research domains related to social exclusion. The following section discusses the AI methodology used to elicit FCS and HRGs voices in the HIV programme in India.

4.5. AI Creates Space for CRs to Share Perspectives

As discussed in Chapter 1, the Indian government has utilised quantifiable outcomes to measure the effectiveness of the HIV counselling programme among HRGs and has neglected to evaluate social factors. The HIV programme has exhibited inequalities and situations of oppression among FCS. Additionally, the prevailing stigma towards HRGs impacted their safe and voluntary access to counselling services (McKinley, 2014.; Sawant, 2012). Indian policymakers have not emphasised these social realities while designing the HIV counselling programme (Meehan et al., 2015). The quantitative nature of reporting has ignored the significance of psychosocial aspects of HIV counselling that are core to these services. These realities, power disparity, discrimination, negligence, and marginalisation are vital to consider in co-designing any PHP (Giacomini, 2010). Besides, due to the influence of multi-layered factors encompassing social, political, economic, and cultural domains, the issues faced by HRGs are complex (Baral et al., 2010). Social situations experienced by HRGs, such as stigma and discrimination, increase their vulnerability (Altman et al., 2012) and further adds to the challenges in their access to HIV prevention services (Guadamuz, Goldsamt and Boonmongkonet, 2015).

As discussed earlier, AI has been identified as an appropriate theoretical framework perspective that supports a methodological space for vulnerable groups in the context of organisations who can then elicit their voices as CRs (Grant and Humphries, 2006). Among other methodologies, the examination of experiential knowledge and sensitive social realities of such groups benefits the most from a critical lens that values participation and empowerment (Tremblay and Richard, 2014). It enables them to suggest change strategies, shapes a mutual learning process for shared decision-making, and, as such, supports organisational change (Clark, 2002).

4.6. AI Process and Challenges

Out of various empowerment-based approaches that are characteristic of the philosophy of critical theory and fall under participatory research methods, AI is considered well-suited to research in the context of the organisation. AI adopts an agenda for change that foregrounds stakeholders’ viewpoints (Haski-Leventhal, 2015; Rowlands and Rees, 2015).

Since its inception, AI has been a PR approach based on a critical worldview that aims to empower participants as partners or CRs within the organisational context. It has been described as a conceptual reconfiguration of participatory research for a multidimensional view to develop organisations (Cooperrider and Srivastava, 1987). It explores strengths as represented by a group when working at its absolute best to imagine and create positive change for the future (Cooperrider and Whitney, 2005). Informed by positive psychology, AI is a widely published strength-based approach that recognises individuals' strengths as part of organisations and individuals' roles in informing and shaping change (Quinney and Richardson, 2014). However, fundamental to AI is the belief that every group has experienced positive actions in their organisation. They dream of a positive change that can become a reality through their combined efforts (Cooperrider and Whitney, 2005).

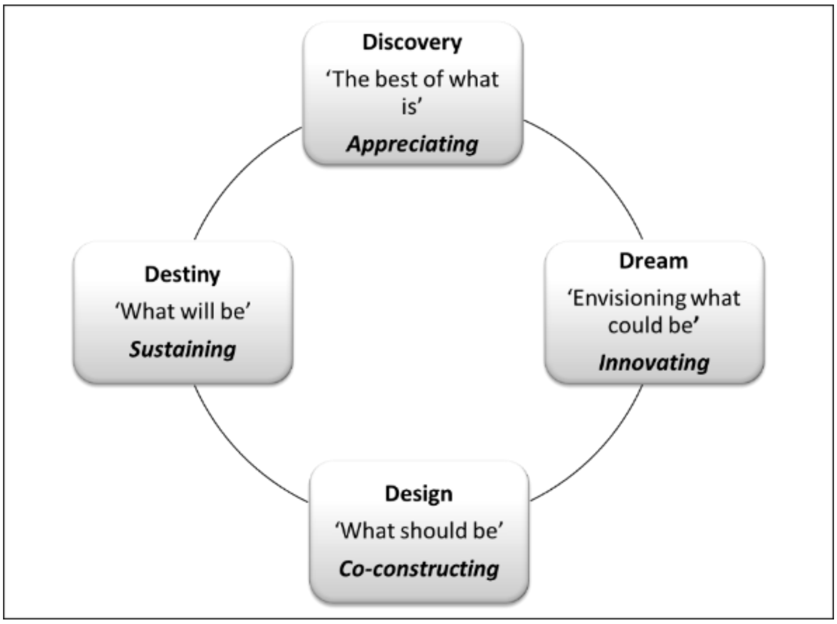
Although there are differences in the interpretation of principles by practitioners, AI adheres to the following six basic underpinning principles (Cooperrider and Whitney, 2001; Wong, 2012):

- The constructionist principle describes reality as socially constructed through language and interaction, and inquiry generates an understanding of future possibilities.
- The principle of simultaneity explains that inquiry and change go hand in hand. It states that change begins at the inception of inquiry and continues via the questions we debate.
- The poetic principle states that what we study influences what we discover. Like poem interpretations are endless; past, present, and future are open to interpretation.
- The narrative principle states that daily interactions recreate the organisation's story, and as we weave stories, we create lasting bonds.
- The anticipatory principle explains that we collectively imagine our future, and these images influence our current behaviour.
- The positive principle states that positive thinking is required to keep the momentum for bringing change.

Cooperrider (1986), the architect of AI methodology, promoted a practical application of appreciative philosophy to improve organisational behaviour. Later, it emerged as a research technique. While there is no single accepted model for AI, the 4D cycle (Discovery, Dream, Design, and Destiny) provides a good starting point (Cooperrider and Whitney, 2011), visually rendered in Figure 4.1.

Figure 4.1

AI 4D Cycle



Adapted from Ludema and Fry, 2008

AI researchers incorporate various research methods within the phases of AI (Murray, 2012). In healthcare research, AI uses tools like semi-structured interviews (Dematteo and Reeves, 2011), observation (Dewar and MacBride, 2017), focus groups (Murray, 2012), practice meetings (Carter et al., 2007), workshops (Trajkovski et al., 2013), and whole group summits (Richer et al., 2010).

I used FGDs as a data collection tool for the current research using AI's 4D framework. FGDs provided a platform for CRs to share their experiences and enabled them to ask questions, and give feedback, which helped to identify strengths, values, and positive aspects of a situation. By including multiple perspectives and voices in the process, FGDs can also help promote a sense of inclusiveness and collaboration, essential for building trust and creating shared solutions.

The following section examines methodological issues that were contemplated when conducting AI-based FGDs. FGDs are widely used in qualitative research and should be conducted correctly to address and solve these issues (Jakobsen, 2012). Arguably they remain a more acceptable tool for data collection and a medium for gaining views from vulnerable communities. Furthermore, AI involves the co-construction of knowledge and attempts to keep FGDs participatory.

FGDs have been considered an artificial setting, controlled by the researcher, and, thus, doubted for their validity compared to more naturalistic environments (such as observations). It entails creating appropriate conditions for interaction among focus group participants ((Jakobsen, 2012). During the fieldwork in Una, it was challenging to get CRs to participate more than once, considering the migratory nature of HRGs and variant rosters of HIV counsellors and other FCS. However, as a trainer for FCS, I had a sense of familiarity with the nature of clients and the work environments of the counsellors. This helped to schedule FGDs based on the convenience of CRs.

Ensuring quality in data generation with FGDs requires thorough attention to issues of authenticity, research positionality and power (Jakobsen, 2012). Any pre-existing acquaintance between CRs may lead to conflicts between CRs. HRGs who participated in FGDs knew each other, which may have prevented a thorough sharing of experiences. To tackle this challenge, I clarified any such confusion with HRGs or their representative during or after FGDs without disrupting the active discussion or creating smaller breakout groups with 2-3 members groups based on their preferences to allow more private discussions.

CRs utilised several other tools including mind mapping, brainstorming, and drawings to discuss their proposed plan's feasibility. These tools were utilised for visual representation of CRs' thoughts, and helped to encourage creativity and divergent thinking, uncovering new insights and possibilities. They allowed CRs to think outside the box and to build on each other's ideas. They helped to surface hidden assumptions and beliefs, and reveal new ways of thinking. Drawings were a tangible and accessible way for HRGs and FCS who felt more comfortable visually expressing their thoughts rather than speaking. The CRs decided on the activities which helped them deduce solutions from discussions at every stage of AI. Based on the above AI cycle (Figure 4.1), I devised the following four questions to guide the FGDs.

1. **Discovery:** Appreciate "best of what is"- Identify organisational processes that work well
   What was your best HIV counselling service experience?
2. **Dream:** Imagine "what could be"- Envision processes that would work well in future
   How do you envision the best HIV counselling programme?
3. **Design:** Determine "what should be"- Plan and prioritise processes that would work well
   How would you design such an HIV counselling programme?
4. **Destiny:** Create "what will be" - Implement the proposed design
   How do you visualise achieving this design in real programme settings?

Through these questions, I created a space for the participants to envision the HIV programme's future in the Una district. The process aimed to foster positive relationships between the FCS and HRGs and build on the programme's present potential (Klomp, 2012). During FGDs, CRs recalled their success stories and introduced their future dreams, while I facilitated the discussions. The CRs combined positive aspects of HIV counselling effectiveness to develop a collective vision through the above process and tools.

With a particular focus on the positive, AI has not been without its critics. Critiques of AI, especially those conversant with its process and underlying theory, have questioned the exclusive focus on the positive (Bushe, 2012; Fineman, 2006; Golembiewski, 2000). They argued that such a singular focus is elusive when social reality indicates the opposing forces at work, especially as experienced by vulnerable groups. Golembiewski, a positivist researcher, argued that AI ignored generating valid and expressed concerns and advocated anti-research. Organisational development scholars, like Golembiewski (1998, 2000), preferred a system that identified dysfunctional features of the organisation and not solely considered the social constructionist worldview of people in the organisation, accenting what works well.

A common concern about AI was that positive stories would invalidate negative organisational experiences during the discovery stage (Barge and Oliver, 2003). These stories would repress potentially essential and meaningful conversations that might otherwise occur (Egan and Lancaster, 2005; Fitzgerald, Oliver and Hoxsey, 2010). However, contrary to Golembiewski's criticism, Bushe (2012), a prominent AI researcher, commented that AI is not interested in discovering '*what is*' but allows a collective to uncover '*what could be*'. Fineman (2006) also critiqued AI for being based mainly on positive emotion. He argued that AI researchers were less suspicious than other critical theorists. Bushe responded that what AI advocated was equally essential for human relations within a structure of the oppressor and oppressed, claiming its application in critical-theory-driven AI interventions.

Scholars have criticised AI for not being a rigorous research approach. As discussed in the previous section, AI is a participatory research methodology following a 4D framework that uses positive-valance questions to discover, dream, design, and consider a research's destiny. However, as stated above, Cooperrider never looked at it as a research technique adhering to a step-by-step method but more as a strength-based approach to improving organisational behaviour.

In its initial stages of development, AI was a research discipline that focused mainly on organisational development in the discipline of management (Carter, 2006). Its application has expanded towards health care organisations over the last decade (Richer et al., 2009). This initial focus on AI as a management tool came before methodological applications of AI. In turn, several researchers devised their own ways to use AI in research (Bushe, 2011). However, Bushe (2011) argued that it was inevitable to avoid negative connotations when exploring organisational and social factors affecting public health. Stakeholders may disagree with AI thinking they fall outside the scope of AI-based research. The positive orientation of AI may cast a "side shadow" that may marginalise the participants' viewpoint (Boje, 2010). To solve this issue, Bushe developed a 5D process, adding a 'Define' stage that required defining problems before exploring the best experiences. Current research follows Cooperrider's 4D process where 'Define' has been included within the 'Discovery' stage (Cooperrider and Whitney, 2007).

AI created a space for participants to share their ideas on improving the programme while keeping the voices of vulnerable HRGs at the core. The participants acted as research partners in deriving these ideas (Wicks and Whiteford, 2006). This approach foregrounded the voices of HRGs and FCS and provided a basis for change. The voices of those involved in research, described as 'CRs,' remain central to any proposed actions (Giacomini, 2010; Grant and Giddings, 2002).

The study presents the viewpoints of FCS and HRGs for improving the programme in Una, as they are vital stakeholders in the programme. It aimed to draw inferences on power dynamics faced by HRGs, their views on the programme, and their ideas on improving the programme. The application of critical theory for this research follows a participatory approach where it places the voices of vulnerable HRGs at the core. This approach illuminated and analysed the experiences of HRGs and FCS on the counselling programme and associated gaps in the HIV programme. The adoption of AI helped in exploring complex issues through engagement with HRGs and FCS. The research question "How can the Indian HIV counselling programme in Una district be more effective using AI?" aimed to address this critical issue.

To conclude, this section, it is essential to restate the primary reasons for using AI as a methodology for this research. AI proved suitable for learning about the positive contributions of the HIV programme for Indian HRG communities and promoting ongoing improvement in the services. Since this methodology has a foundation in theory and the authenticity of findings, AI has a robust health policy application (Clouder and King, 2015). These learnings helped in the evolution of the data collection and analysis process and further informed the research design.

4.7. Field Study

This section describes the study design and includes the challenges faced in recruiting the CRs—FCS and HRGs—due to their fear of disclosure and desire to keep their identities confidential and private. The importance of a comfortable and safe space where CRs can engage in discussions on HIV counselling and programme effectiveness (Cahill, 2007) is highlighted. As a novice researcher, my biggest challenge was incorporating the AI concept into the data collection and analysis process, and ensuring it was suitable for the context of the Una district. The duration of fieldwork was 2 months, from mid-December 2015 to mid-February 2016. Reflecting upon my previous experiences, I recollect why I chose AI as a methodology in the following section.

During my interactions with the HIV counsellors in northern India, I discovered that HRGs' counselling needs were not addressed by the national programme in several northern states. The programme required counsellors to deliver counselling sessions as per the programme guidelines. However, the programme overlooked that counselling guidelines did not give sufficient importance to these communities' sociocultural needs or spiritual context.

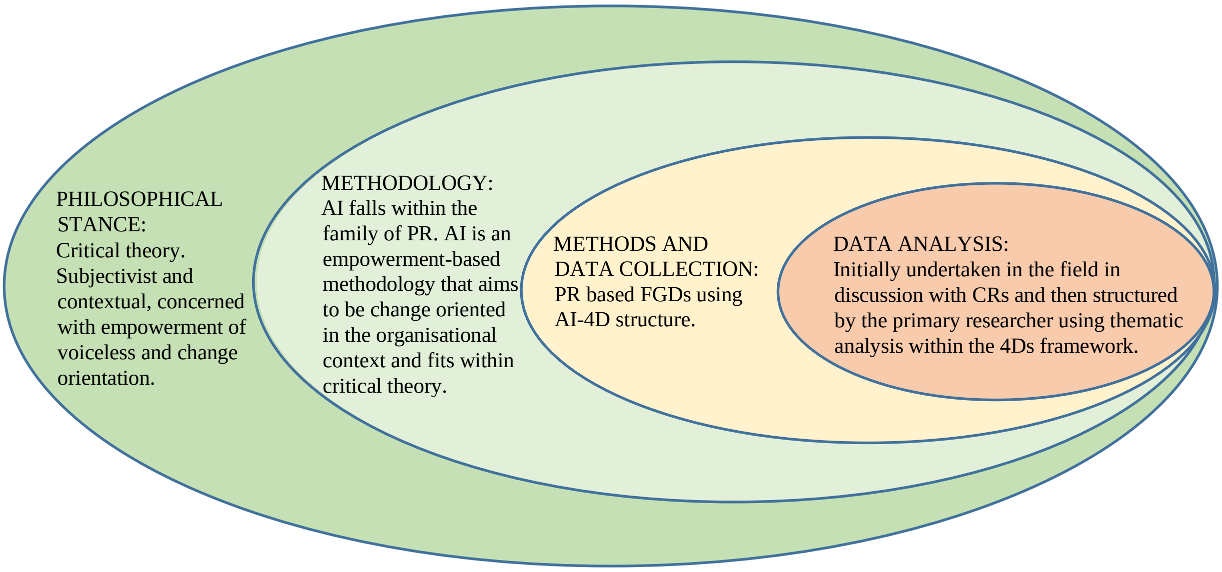
On further examination of the HIV programme in these states, it was noticed that although HIV *counselling* had been studied through the lens of psychology and psychotherapy, its *evaluation* was founded on biomedical principles and was predominantly quantifiable in nature (Bor, Miller and Goldman, 2013). This statement is true for India, where external agencies primarily fund the HIV programme (see Chapter 3).

India is a country where the power dynamics between superiors and lower staff members are accepted as a standard affair. Consequently, the FCS or HRG clients never have a say in programme activities. FCS and HRGs are left to deliver and receive HIV counselling services following a blueprint approach. The programme evaluation is largely dependent on the results of closed-ended questionnaires, and the counting of variables like the number of counselling attended, duration of counselling sessions, treatment taken, and the number of condoms distributed. These learnings highlighted the need for a qualitative methodology to explore improvement opportunities for the programme.

Epistemologically, quantitative research is associated mainly with explaining a particular phenomenon within the boundaries of the hypothesis, while qualitative research relates to exploring it beyond the pre-imagined boundaries of the research question (Crotty, 1998). Likewise, HIV programme effectiveness is judged on quantifiable variables encapsulated within predefined models, not considering social factors in their making. Participatory methodologies specifically align the objectives of the current study and examine these factors aimed to address the gaps in delivering effective HIV counselling services.

Figure 4.2

AI-Based Design for the Study of HIV counselling programme effectiveness in India



Adapted from research onion (Saunders et al., 2012)

The AI 4D stages represented the central structure for this research design. Table 4.1 positions AI within the participatory research methods under the overarching critical theory framework and links it to the study's philosophical stance. Table 4.2 presents how the distinct stages of AI apply in the current context.

Table 4.1

Linking the Philosophical Stance with the Research Question.

Model	Links to AI	Links to study
Perspective: Critical theory	Meanings and interpretations, not solely on measurable facts, challenging the ways of thinking	Co-constructing with coresearchers how they view their role and what they see as their contribution to HIV counselling. Finding alternatives to improve HIV counselling
Context: Participation	Interested in the co-construction of knowledge and facilitating change	Discovering what coresearchers do, what works and reflecting on what should be and what could be

Table 4.2

Linking the Phases of 4D with the Research Process

AI phase	Description	Application to study
Discovery	CRs explore what works well, what gives life to their work	HRGs consider what used to work well in HIV counselling services and share high points in their experience. FCS consider how they have delivered effective support to HRGs
Dream	CRs envisage what could be	HRGs and FCS discuss what would represent an ideal HIV counselling service
Design	CRs consider ways to develop	HRGs and FCS discuss changes that would improve the current HIV counselling service.
Destiny	CRs engage in planning	HRGs and FCS discuss improvement opportunities for the future of HIV counselling services

The AI-based FGDs, the data collection tool for this research, were pre-tested a few months before fieldwork. Studies suggest that it is ideal to do a pre-test of the methodology before conducting the actual data collection. Such pre-tests train and expose the researcher to practical issues when using data collection tools, especially when discussing sensitive topics (Sutton and Austin, 2015).

As I was relatively inexperienced in conducting AI, I invested time in pre-fieldwork practice runs and preparation. AI is best taught and learned through blending theories and practice (Sharp et al., 2018). This idea encouraged me to organise and facilitate four practice sessions that prepared me to communicate my research design and perform the planned research tools. Each FGD practice took about 2 hours and proved valuable. I rehearsed the research tool a couple of months before my fieldwork. Ideally, studies conduct such pre-tests with participants of similar characteristics to the potential coresearchers (Herr and Anderson, 2014). Therefore, I requested several frontline healthcare workers from Auckland with experience with PLHIVs to participate. They helped me understand and apply the principle of participation and collaboration and gain skills to create a shared space and build trusting relationships with the CRs—HIV FCS and HRG.

A successful AI allows the CRs to have open, informal communications that support a collaborative research process (Bushe, 2007). I noticed that an overly structured approach and controlling actions like writing the answers on a flipchart and steering talks did not give value to participation, collaboration, and trust-building. Therefore, I 'handed over the stick' to the participants and allowed them to lead the discussions (Chambers, 2006) to deliver the desired outcomes. I also realised that when I tried to rush the debate without giving enough time to the CRs, their views may not have been fully expressed (Kemmis et al., 2014). As the above values were core to any AI, I only needed to be a facilitator and avoid pre-meditated discussions. These pre-fieldwork discussions helped modify the research approach to be more effective and participatory, allowing CRs to make discoveries, describe their dreams, and design their destinies around the programmes.

The local support systems have an essential role in any research, especially when dealing with social and political challenges found in the field. These support systems include local authorities and NGOs, which are essential for approvals, advertisements, recruitments, and basic requirements of food and shelter and emotional support during fieldwork (Smith, 1999). The Una district hospital helped get the research study's locality approval. There were different venues for conducting FGDs provided by the hospital and the NGOs involved in the recruitment process. The expense of lunch and snacks was shared between hospital authorities and through the research budget. No accommodation was sought.

Before my fieldwork I had developed a strong connection with the HIV stakeholders at the Una district. After gathering information about the public health operations in Una, I consulted a field mentor, developed links with the district health authorities, and networked with relevant local NGOs to recruit HRGs for FGD. I researched the district hospital's structure and functioning, which helped me understand the programme's hierarchical positioning within the district public health system. This helped me to complete the situational analysis described in Chapter 2. This decision to make connections proved beneficial as it eased the logistical feasibility of the fieldwork and added to its local credibility. Arrangements commenced in December 2014 and took several months to complete.

From December 2014, I was in regular communication with my contacts at Una to initiate collaborations with the FCS and HRG clients—IDUs, FSWs, MSM, and migrants. The fieldwork plan received the local authorities' approval in 2015 after a discussion with the Chief Medical Officer (CMO) at Regional Hospital, Una district, Himachal Pradesh. The process of ethics approval from AUT is discussed in later sections. For recruiting FCS, I met the district HIV counsellor and staff members from the district hospital and selected NGOs involved in outreach activities. These NGOs delivered primary health services to PLHIVs and HRGs. FCS and HRGs closely participated in developing the advertisement for potential CRs. After minor alterations, including removing terms that potential CRs or laypeople might question (e.g., rather than using 'client', 'HRG' was preferred and applied in the thesis), the participants approved the design and content of the advertising.

The district counselling centres, and local NGOs disseminated the advertisements. The HIV counsellors, NGOs, and HRG community members also supported the recruitment process by spreading word about FGDs to their peers. They recognised my role as a facilitator by introducing me to their peers, which helped me build rapport with the community. Interacting with them revealed that Facebook or social media were not helpful for advertisements as most HRGs in Una had no access to smartphones. Those using social media were unwilling to use it for HIV-related posts.

These consultations lead to significant modifications in the plan for fieldwork. Earlier, FGDs were planned in a meeting room separate from the hospital building's crowded floors, providing a private and confidential space for the participants. However, based on these consultations, additional meeting spaces were organised for FGDs who faced difficulty visiting the hospital premises for several reasons. These meeting spaces were closer to NGOs or HRG hotspots. Three NGOs accommodated this request by allowing us to conduct FGDs in their meeting rooms, which were discreet and separate from residential areas.

The other modification resulting from these consultations was to have two separate FGD groups. Earlier, the fieldwork design had planned to conduct common FGDs with two groups combined for collaborative design thinking. However, HRGs preferred to have separate FGDs from FCS. They felt that combined, FGDs might unnecessarily reveal their identities to the FCS who may otherwise not meet them. They were also overwhelmed by the FCS's presence and feared they might not express their perspectives well.

Additionally, there was an assumption of a higher chance of conflict between FCS and HRGs if put together in FGDs. Therefore, I kept FGDs for the two groups separate and conducted one FGD in a combined fashion with only those who consented to the arrangement. The key themes that emerged from discussions with HRGs were used as cues for other FGDs and were related to the other FGDs during data analysis.

With my experience as a locally based HIV researcher, I understood the difficulties HRGs faced (Iwasaki et al., 2014; Labonte, 1997) and conducted data collection in strictly private surroundings by arranging convenient locations based on

CRs’ preferences. Being fluent in the local dialect of the Una district—a mixture of Hindi, Punjabi, and Himachali—I efficiently communicated with the CRs to understand their contexts, emotions, thoughts, and feelings using an empowerment approach I learned while studying AI.

4.8. Selection of CRs

The CRs were invited through various NGOs and advertisement displayed on the notice board of the hospital. They were divided into two groups based on the study’s needs and scope (Boeije, 2009). The first group consisted of FCS delivering HIV counselling services and support to HRGs and general populations. The second group comprised HRG community members who were registered beneficiaries under the HIV programme. Participatory research focuses on relationship building and extracting collaborative information, an outcome that requires small groups. Therefore, at most, 5-7 CRs participated in each FGD. The following points clarified the eligibility criteria for being a coresearcher:

- Age: 18 years or above
- Frontline counselling worker: An employee of Una District AIDS Prevention and Control Unit (DAPCU) or an affiliated NGO under Una DAPCU who is associated with the HIV counselling programme.

OR

- HRG client: A client registered under National AIDS Control Programme services at Una district and categorised as an HRG, a community that includes MSM, IDUs, FSWs and members of the bridge population; and who had received at least one HIV counselling session in the past 12 months.

The inclusion criteria were decided based on the definitions of an HRG client—MSM, IDUs, FSWs, and bridge population, including SMM, given by the Indian HIV programme borrowed from the UNAIDS (2015). Although there were HRGs below 18 years of age, only those 18 or older were included in the study. The key reason is that the Institutional Review Boards (IRB) mandate that people under 18 require their guardian's permission to participate in the research. Also, given the traditional orthodox nature of Indian families and their role as a primary social regulator for young members (Thomas, 2012), Indians are unlikely to disclose their sexual orientation or addictive behaviour to their families. Hence, requesting the guardian's consent could seriously impact participants who will not then be allowed to participate in discussions.

Although Kemmis and McTaggart (2005) commented that facilitators could take on the role of CRs given their commitment to social change, I tried to act only as a facilitator and avoided any steering of discussion. However, in cases where the discussion lost direction, like conversations on an unrelated topic or repetition of similar points, I mildly steered the discussions back to the research question. For instance, during the Discovery stage, the initial discussions were on criticising the HIV control programme in Una and what had gone wrong, specifically with the HIV counselling programme in Una. AI is important to diagnose and change organisational culture (Cameron, Dutton and Quinn, 2003). After a few rounds of discussions, the AI importance was revisited, bringing back the agenda of positive social change and directing discussions towards strength-based responses.

Out of 30 CRs, 14 were from Punjab, 10 were from Himachal Pradesh, and the remaining six were from other states. However, all CRs were based in Una. Among these, 8 had studied in intermediate school; 13 had attended tertiary education; 7 had attended only primary school. Most of the tertiary-educated had either a degree in psychology or a diploma in nursing. There was one CR who had a diploma in medical laboratory sciences.

FCS were employed as counsellors, lab technicians, nurses, or NGO outreach workers. Most FSWs and MSM worked as sex workers. However, they had other regular jobs as cleaners, labourers, stage performers, truck drivers, or peer educator at the NGO.

4.9. Data Collection and Analysis

AI proposes a participative approach where data collection and analysis are integrated as a collaborative exercise with participants, and both take place in the field (Mace et al., 2014). Instead of collecting data passively and analysing/making sense of it at the desk, the meaning of the data are co-constructed with participants in real-time during FGDs. Participatory research, especially AI, enables collaborative reimagination and is a combined analytical process. The process involves asking questions that initiate the discussion, drawing on their answers, and generating debate in the focus group. I gave my feedback on what I understood and facilitated the group to ensure they understood each other. Likewise, I made sure that I developed mutual understanding with them. As a result of interactive data collection and analysis, the answer to my research questions, driven by the principles of AI (the 4D), were constructed collaboratively. The data generated were rich, culturally appropriate, and organic, as they were co-constructed by the CRs.

Table 4.3

Details of CRs

A. FRONTLINE WORKERS

S.NO.	Name*	Age	Category	Occupation	Education	Gender	FGD
1	Kalyan	34	Frontline	NGO Counsellor/Nurse	Tertiary	Female	1,2,3
2	Hirapi	26	Frontline	NGO Counsellor/Nurse	Tertiary	Female	1,2,3
3	Raadee	34	Frontline	NGO Counsellor/Nurse	Tertiary	Female	1,2,3
4	Yogini	30	Frontline	NGO Counsellor/Pharmacist	Tertiary	Female	1,2,3
5	Natu	50	Frontline	District Counsellor	Tertiary	Male	1,2,3
6	Lat	40	Frontline	District Lab Technician	Tertiary	Male	1,2,3
7	Hira	40	Frontline	NGO Project Officer	Tertiary	Female	1,2,3
8	Heman	40	Frontline	NGO Project Officer	Tertiary	Male	1,2,3
9	Oni	30	Frontline	NGO Outreach	Secondary	Female	10,11,12
10	Paul	34	Frontline	NGO Monitoring	Tertiary	Male	10,11,12
11	Vinny	38	Frontline	NGO Outreach	Tertiary	Female	10,11,12
12	Rana	44	Frontline	NGO Accounts	Tertiary	Male	10,11,12
13	Osee	40	Frontline	NGO Clerk	Tertiary	Female	10,11,12
14	Seeku	34	Frontline	NGO Outreach	Secondary	Female	10,11,12
15	Ritu	38	Frontline	NGO Admin	Tertiary	Male	10,11,12

B. HIGH-RISK GROUP (HRG) CLIENTS

S.NO.	Name	Age	Category	Occupation	Education	Gender	FGD
1	Komu	38	MSM	Peer Educator/Outreach	Intermediate	Male	4,5,6
2	Kalini	27	FSW	Peer Educator	Intermediate	Female	4,5,6
3	Sewa	37	FSW	Peer Educator	Primary	Female	4,5,6
4	Hirant	29	SMM	Peer Educator	Intermediate	Male	4,5,6
5	Sam	32	SMM	Peer educator	Primary	Male	4,5,6
6	Nathan	34	SMM	Peer educator	Intermediate	Male	4,5,6
7	Yog	45	IDU	Peer Educator	Intermediate	Male	4,5,6,7,8
8	Maharaj	38	IDU	*Baba*/Homeless/Begging	Primary	Male	7,8
9	Gabu	39	IDU	*Baba*/Homeless/Begging	Primary	Male	7,8
10	Chela	40	IDU	*Baba*/Homeless/Begging	Primary	Male	7,8
11	Avin	29	IDU/LDT	Trucker	Intermediate	Male	7,8
12	Abby	23	MSM	Peer Educator	Intermediate	Male	9
13	Rambo	25	MSM	Construction worker	Primary	Male	9
14	Nanny	22	MSM	Contractor	Intermediate	Male	9
15	Tichu	28	MSM	Stage performer	Primary	Male	9

* Pseudonyms have been used to conceal participants' identities

Table 4.4

FGD

FGD	CRS	Members	Location	Ai phase	Time	Day
1	Frontline workers	8	Hospital	Discovery	2 hours	1
2	Frontline workers	8	Hospital	Dream	2 hours	1
3	Frontline workers	8	Hospital	Design, Destiny	3 hours	2
4	HRGs (Mixed*)	7*	Hospital	Discovery	2 hours	3
5	HRGs (Mixed*)	7*	Hospital	Dream	2 hours	3
6	HRGs (Mixed*)	7*	Hospital	Design, Destiny	3 hours	4
7	IDUs	5*	Centre Park	Discovery, Dream	4 hours	5
8	IDUs	5*	Centre Park	Design, Destiny	3 hours	5
9	MSM	4	NGO	All four phases**	4 hours	6
10	FCS	7	NGO	Discovery	2 hours	7
11	FCS	7	NGO	Dream	2 hours	7
12	FCS	7	NGO	Design, Destiny	2 hours	8

* FSWs, IDUs, MSM, and SMMs participated in these FGDs.
** This FGD involved all 4D phases together.

In total, 32 respondents expressed interest in FGDs, but 30 participated. Fifteen were HRGs (across 6 FGDs), and 15 were FCS (across 6 FGDs) (see Table 4.3). Every FGD involved one or more of the four stages based on the 4D model of AI, and 1 to 2 hours were allotted to each stage. A break of 5 minutes was provided after every half-hour discussion, and after 2 hours, another half-hour break was provided. A provision of tea or coffee and light snacks during discussions was made. Lunch was provided, keeping the preference of CRs in mind. In total, data collection took eight days of FGDs and 33 hours of audio recordings. As indicated in Table 4.4, 12 FGDs were held in the hospital meeting room, eight at NGO meeting rooms, and four were conducted at a park next to an NGO.

Every FGD started with rapport building with the CRs and sharing knowledge using a PowerPoint presentation and printouts of the slides in the local language. Although there was slight discomfort in the first few minutes, the atmosphere of the focus group became relaxed and informal after the rapport building. The CRs were curious to know the other CRs' opinions about the HIV counselling sessions delivered in Una. I felt accepted by the group in this relaxed environment, and the discussions flowed well.

The cues used for FGDs followed a funnel-based discussion. The discussion began with a less structured approach that emphasised free discussion and then moved towards a more structured debate with a more tightly controlled ending (Morgan, 1997). Additionally, while in Una, I undertook a programme document review used in Chapter 2 and visited local NGOs, HRG hot spots, and counselling centres to observe HIV counselling services in the district. The process was documented, and the discussions audiotaped. Flipcharts and markers were used to draw their dream counselling session, mind maps, and discussion notes. CRs then explained these drawing and mind maps, which were recorded and transcribed. Every event during the FGDs was noted, and any biases or challenges recorded in the field diary. Although there was a FGD schedule to follow, it is worth emphasising that the discussions gave enough time to each stage of AI and were collaborative, interactive, and co-constructed.

The participative intentions of the FGDs gave importance to creating knowledge in a co-constructed manner. Due to my experiences with the HIV programme, research positionality, and networks with the CRs, I was easily treated as "one of us". They considered me as someone who could understand their situation. I ensured that I built a good rapport with them by meeting them one to one before FGDs. In these meetings, I explained the research question, emphasised its importance to their work, and provided assurances that I would abide by the guidelines of ethical consent, which helped them to trust me more.

During FGDs, there were enough ice-breaking and casual interactions to make sure that FGDs were comfortable. CRs were given provision to have one-to-one interaction in cases where they needed help or clarifications. A koha (e.g., a food voucher) was given to them before the start of the FGD to avoid them seeing it as a motive to participate. In some instances, where the CRs felt uneasy from discussions, a counsellor supported them in an easy exit. In such situations, the CR was assured that no information shared during FGDs would be discussed outside and they were linked with the health practitioner at the hospital for more help.

Participatory approaches, like AI, offer a theoretical framework to think about these issues and a set of conceptual tools to address these gaps, which have been detailed in previous sections. Following a typical AI model, the data-gathering process included the following four stages—discovery, dream, design, and destiny (International Training Centre of the International Labour Organisation [ITCILO], n.d.; Lustig and Ringland, 2010). However, as discussed above, the CRs' main discourse was around discovery and bringing organisational changes to the programme. In keeping with the concept, the AI-based data gathering process aimed to build discussions around what has worked well in the programme more than trying to fix the programme shortcomings (Seel, 2008). The four AI stages are described below:

1) **Discovery:** This phase was about the best of what is and what has worked in the past (Elliott, 1999). In this stage, the CRs discussed their best HIV counselling service experience (Elliott, 1999). The CRs shared stories, drawings, and conversations amongst themselves. The group identified common themes during

the discussion and explored them further. At the end of this stage, the group drew out common themes to collectively describe the best HIV counselling service.

2) **Dream:** This phase was about envisioning the best for their future (Carter, 2006). In this stage, the CRs used aspirational stories and experiences to inform each other about their future envision (Carter, 2006), imagining the programme was functioning at its best (Coghlan, Preskill and Tzavaras Catsambas, 2003). The CRs used the themes and stories of this phase to develop ideas for their preferred future. They participated in visualisation exercises like drawing pictures of the future or making a flow chart (Watkins and Mohr, 2001) and told futuristic stories of what they imagined it to be (Boyd and Bright, 2007). At the end of this stage, the CRs drew out themes from the dream-making activities to form collective visions.
3) **Design:** This stage was about planning and designing a ‘dream’ HIV counselling service based on the ideas derived from the previous two stages. These ideas created by CRs from the dream phase developed into a robust and actionable vision for their future (Ludema and Fry, 2008; Coghlan, Preskill and Tzavaras Catsambas, 2003). In this stage, the CRs brainstormed using sticky notes and flip charts to draw possible designs to develop their collective vision into reality. They drew themes from the above stories and dreams to present their results.
4) **Destiny:** This final stage was about the future of the design. The CRs used mind mapping, stories, and drawings to express their thoughts. They devised broad objectives on achieving these aspirational ideas and what resources they would need to make them a reality. Like all other stages, this stage was also dependant on how CRs decided on the conduct of activity and how they thought the solution would be deduced from FGDs.

After discussions, I journaled the day's activities. I identified the main themes of my data to derive the key points that answered the research questions. Following Table 4.5 summarises the different phases and relate them with the questions that AI poses.

Table 4.5

Summary of the Content and Facilitation of Each Session

Stages	AI phase	Aims	Information given and questions posed
First	***Discover***	Welcome CRs. Reiterate the purpose of FGD. Facilitate discussion on CRs' perspectives about the organisational processes that work well.	Slideshow on context and purpose of research. Question: What was your best HIV counselling service experience? CRs asked to think of what they appreciated about the HIV counselling experience that they had in the past. Invited to share a positive experience and what they valued about the service, or the people involved.
Second	***Dream***	Recap on highlights from the previous FGD stage. Discuss the examples of effective HIV counselling shared in the previous stage. Imagine "what could be"- Envision processes that would work well in the future.	Recap the question from the previous stage and link it to this stage. Question: How do you envision the best HIV counselling service? CRs discussed what they thought was an ideal practice and envisioned how the existing services could be more effective.
Third	***Design and Destiny***	Recap on discussion focus from the earlier two stages. Determine "what should be". Plan and prioritise processes that would work well. Create "what will be". Implement the proposed design.	Remind the group of the questions posed last time. Question: How would you design such an HIV counselling service and visualise it to achieve this design in real settings? CRs discuss how they design an effective HIV counselling service when given the power to change and how they would implement the new design in real scenarios.

As a reflection of the AI-based participatory discussions, the CRs appreciated the opportunity to be agents of change, which is the critical agenda of AI. Most Indian public health organisations are hierarchical and bureaucratic, where the interplay of power and position is a frequent practice. A critical lens helped give value to these power differences and appreciate what the frontline staff and HRGs felt about the programme and services, and their improvement. This process was instrumental in bringing positive ideas by CRs; CRs expressed that it was the first time their perspectives towards HIV counselling services were heard and understood which they believed was the reason for their positivity.

On returning to Auckland, the FGD audio recordings were transcribed, thematically mapped, and analysed further. These FGDs generated a large amount of complex multilingual data to be transcribed, translated, and analysed, which required considerable time. The audio recordings were in a mixture of Hindi, Punjabi, and English languages. A few words in Himachali (the local dialect of Himachal Pradesh) were not difficult to translate due to their similarity with Hindi and Punjabi. These recordings were translated into English and transcribed using NVivo, Microsoft Word, and an audio player as transcribing tools. Using NVivo as a transcription tool was helpful as I created timestamps along with the audio recording, which could be revisited in case of confusion or re-listening. Audio recordings and transcripts were shown to supervisors from time to time for their conformity to methodology and ethical conduct.

The official language the district HIV programme used for their documentation and reporting was English, which was easy to comprehend and analyse. Additionally, I was able to read the local documents with ease, which were written in Hindi and Punjabi, and understood the many notes, flipcharts, and drawings from FGDs in those languages.

Although time-consuming, transcription helped in familiarisation with the data. While transcribing, I recorded all verbal utterances to their original nature (e.g., putting pauses and punctuations where required). Data were then translated into English. A few words/phrases lacked full subtlety of meaning or significance when translated and were kept in their original language. This process helped in developing a thorough understanding of data, facilitating close reading and the interpretative skills development needed to analyse the data. After translation, the transcripts were checked against the original audio recordings for accuracy (Braun and Clarke, 2006).

Additionally, I transcribed the audio recordings to refine themes and their inter-relationships, thereby furthering my analysis. As an experienced quantitative researcher, I acknowledged that I gave value to using computational tools for analysing data. However, I analysed the data using my research lens in this qualitative research thesis. There is a dearth of literature showing the application of AI as a method of analysis; usually, researchers pair it with thematic analysis to ease the analysis part. However, Braun and Clarke (2006) stated that thematic analysis is quite different from critical analysis adopted in participatory approaches like AI, where the emphasis is given to the co-construction of themes rather than desk-based thematic analysis of transcribed data.

Participatory analysis was used to align with the unique requirements of the co-researchers' (CR) culture and situations. Central to this participatory approach was the role of CRs as agents of change, which was particularly significant in the context of Indian public health organisations, often characterized by hierarchical and bureaucratic structures. By employing a critical lens, the researcher was able to acknowledge and give value to the inherent power differences, thereby enhancing our understanding of the perspectives of frontline staff and High-Risk Groups (HRGs) towards the HIV counselling program and its potential improvement. CRs were actively involved in analysing their situation and commenting on possible ways to improve it. This form of participatory data analysis took place directly in the field, where CRs critically engaged with the issues at hand and proposed solutions, thus directly contributing to the data generation and analysis process. This process was instrumental in elevating the voices of the CRs, marking a shift from traditional hierarchical decision-making processes to a more inclusive and participatory approach (Kindon, Pain, and Kesby, 2007). For the first time, CRs felt that their perspectives on HIV counselling services were not only heard but also understood, contributing to their positive engagement in the research. Their insights and suggestions were not merely data points but integral elements of the research analysis, reflecting a unique and critical aspect of participatory research (Ridley-duff and Duncan 2015).

As a public health researcher using AI, my theoretical commitments also informed data analysis. I looked closely at strength-based themes from the transcripts and examined the underlying ideas, assumptions, and conceptualisations which informed my research questions. The data collected were substantial, producing transcripts from 33 hours of FGD recording and interviews. In some interviews, the CRs described their drawings on how they dreamt of their future. After transcribing the FGDs, the data were sorted based on the key themes that emerged from the initial field analysis, which captured the highlights of FGDs. Although few themes followed patterns, their cruciality depended on whether they captured essential points about the overall research question. For example, religiosity as a reason to stay addicted emerged was an important theme from two FGDs with *baba*-IDUs.

4.10. Study Rigour

Rigour can be best described as the ability of a research approach to producing reliable results (Johnson et al., 2020). A positivistic perspective in research measures rigour through internal and external validity and reliability. Internal validity focuses on how well the research procedure was conducted, while external validity looks at how well the study was generalised to other contexts. For qualitative research, rigour uses different criteria to ensure that research is appropriate in relation to its theoretical and methodological underpinnings (Whittemore Chase, and Mandle, 2001). Rigour is demonstrated through criteria of credibility, transferability, and confirmability (Lincoln, Lynham and Guba, 2011). Methods that ensure rigour within the critical theory paradigm are reflexivity, collaboration, and peer debriefing (Creswell and Miller, 2000).

To ensure the credibility of the current research, I spent a considerable amount of time interacting with the CRs. This consisted of attending 12 FGD meetings of 2 hours each, as additional meetings outside of FGDs, and visiting the associated NGOs and counselling centres. This extended time and interactions allowed us to bring trust and openness in our discussions (Creswell and Miller, 2000; Kemmis and McTaggart, 2005) and increased my understanding about the coresearchers. As required by HRGs, FGD participation was decided in four ways: (i) FGDs with FCS and HRGs together, (ii) FGDs for FCS only, (iii) FCS with clients from different HRGs types put together and, (iv) FGDs separated out for each HRG client group. By doing so, FGDs captured a wide range of perspectives, especially those expressed when they were in their comfortable groups. Additionally, clients chose the location of their FGDs. For instance, the IDUs preferred to have FGDs at the places where they hang out and do drugs.

As the results presented the analysis of data primarily generated during the discovery stages of AI, it necessitated me to develop ideas related to dream, design and destiny based on the narratives from the discovery stage to adopt a critical, strength-based perspective. This process also involved referring to other scholarship in which researchers encountered similar challenges and reported on their strategies (Boje, 2010; Watkins, Dewar, and Kennedy, 2016). These complexities suggest that there are instances where AI might not yield the anticipated positive outcomes (Watkins, Dewar, and Kennedy, 2016). Reflexivity played a crucial role in this participatory analysis process, which necessitated a rework or reinterpretation of collected data during fieldwork, ensuring the development of robust themes that accurately reflected the research aims and context. Adopting an iterative approach, where data was revisited multiple times, was essential to delve into that data's depth and nuances. This process allowed for a deeper exploration of hidden narratives (Boje, 2010), such as understanding not just the importance of community support but also how cultural beliefs shape this programme. This active and critical engagement with the data, rather than passive observation, ensured that the research captured the complexities of the HIV counselling programme in Una, offering a comprehensive insight into the topic. The reflections generated strength-based themes from the transcripts and examined the underlying positive ideas and empowerments. This approach aimed to integrate data analysis with theme development, presenting a unified narrative that is sensitive to the research's cultural nuances.

I spent considerable time and attention developing reflexivity by capturing my day's experience and reflections in this fieldwork journal during the 2-hour journey while returning to my residence in Una. I ensured that the research process followed the principles of AI. This journal documented personal reactions, feelings, and thoughts after each interaction, serving as a continuous self-check on biases and preconceived notions. Further, after each FGD I carefully read and re-read the main points the CRs' had written on the flip charts used for collating various ideas, listened to the audio recordings, and ensured that I followed the AI principles as outlined by Cooperrider (Cooperrider and Whitney, 2005). In doing this, I found that after each FGD, there was a significant improvement in my understanding of AI principles and the quality of information gathered.

When exploring the perspectives of FCS and HRGs, I was concerned that my own preconceptions of the programme and my background as a positivist researcher might bias my methodological design (Bourke, 2014). I also was mindful that my biases may affect the quality of AI data as an ex-FCS, a heterosexual married man, and an overseas researcher. To strengthen my reflexivity and further establish the rigour of my research, I hereby expand on the reflections from fieldwork and data analysis. This introspective practice ensured that I remained critically aware of how my identity might shape the research process and that I utilised this learned skill of reflexivity in my career. By maintaining this critical stance and actively seeking feedback, I aimed to ensure that the research remained authentic, rigorous, and accurate to the co-researchers' experiences while minimising the influence of my personal biases.

Recognising that participants from High-Risk Groups (HRGs) might exhibit caution in sharing their experiences due to potential fears of judgment or misunderstanding, I took deliberate steps to foster an environment of trust and openness. Similarly, understanding that the Frontline Counselling Staff (FCS) might perceive me as an authority figure, I approached discussions with humility and genuine curiosity.

Acknowledging the inherent biases and potential influences stemming from my identity as a well-educated heterosexual man was paramount in the research on the HIV counselling programme in Una. Aware of the potential biases my heterosexuality could introduce, especially in interpreting narratives related to sexuality, I maintained a reflexive journal. I repeatedly referred to my PGR9, fieldwork diary with reflections, and notes from flipchart notes to keep me in the proper context.

4.11. Research Ethics

Ethical approval for this research project was granted in accordance with AUT requirements, as applicable in 2015. The AUT Ethics Committee [AUTEC] approved the research under application number 15/387. Additional permission was requested from the CMO Una district for conducting FGDs with HRGs and FCS before starting fieldwork. The Una DAPCU was also informed about the fieldwork being undertaken in their area.

A senior public health consultant, Professor Chaturvedi, functioned as the field supervisor for this research, and Dr Nikhil Sahore acted as my local contact. He ensured that the research met the local regulations for fieldwork and was available for assistance over the phone during the data-gathering process. Although no significant consultation requirement arose during fieldwork, the field supervisor was informed about the progress of data collection. Additionally, support was sought from the CMO’s office, district counselling centres, and four local NGOs for disseminating advertisements on the FGDs. Also, the CRs involved were 18 years of age or above, which made it possible to carry out the discussions without guardian consent.

As my study looked at the various hierarchical segments of the HIV programme in Una, caution was taken to avoid any organisational conflicts. Printed information sheets were provided to interested CRs outlining the required research purposes and level of involvement. All CRs completed a consent form that advised them not to share any information generated during FGDs outside the group. Additionally, the importance of keeping shared information within the group and the need to respect each other’s confidentiality was emphasised at the start of each FGD. The CRs were reminded that they could leave the FGD at any stage of the discussion, considering the sensitivity of the research topic.

Data were collected as audio recordings, notes of FGD, local documents, and flipcharts notes. Access to audio recordings and other data forms was confined to my supervisors and me to safeguard the CRs’ privacy. Identifiable details have been removed from research findings, subsequent publications, conference presentations, and the final thesis to ensure CR anonymity.

The FGDs rooms were separate from the crowded areas of the hospital. Other than that, FGD locations were chosen based on HRGs choice which helped in maintaining discreetness for HRGs and conducting FGDs in locations away from residential areas to avoid them being identified. In all locations, it was made sure that no one outside the group could overhear. No video recordings or photographs of the CRs were taken. During FGDs with the members of the HRG community, a peer educator who was a member of that HRG community was present to assist with the ice-breaking sessions. These peer educators had experience working with their HRG community and knew these CRs well. These peer educators participated in FGDs as regular CRs and (like all participants) signed the confidentiality clause in the consent form before joining.

4.12. Research Considerations

CRs were contacted through advertisements on NGOs and health centre notice boards, through word of mouth, and snowballing techniques giving details of the research project, including methods of ensuring confidentiality and privacy and accessibility to the research outcomes. For more information on the questions asked during FGDs, see Appendix #.

Privacy and confidentiality were of paramount importance. The FGDs were audio-recorded after getting consent from each CR. Pseudonyms were used to refer to client names during discussions. Maintaining confidentiality between the CRs was not possible during the FDGs as the CRs interacted with each other and shared their ideas. In written consent, CRs were advised not to disclose information discussed during FGDs to anyone outside the group.

The CRs were also given the liberty to leave the FGD at any stage. I informed the CRs in writing, as well as verbally at the start of FGDs, that although it was hoped that they would continue to participate, they could withdraw at any time during and after FGDs. I also explained that audio recordings of the withdrawn participants would not be included as part of the study. No videos or photographs were taken. Only audio recordings and notes were used. The anonymity of clients and FCS was maintained during interpretation.

The combination and sequence of methods shown in the next section were designed while being consistent with AI. The findings emerged collaboratively and transparently, and conclusions were discussed informally during FGDs. Preliminary findings were communicated to the district counsellor post data collection. As I am still in contact with the CRs, the district authorities, and the NGOs, I look forward to sending a written summary of the final findings to the CRs.

4.13. Study Limitations

Critical research acknowledges that the researcher is part of the research, and their subjectivity engages in co-constructing a representation of the reality of the phenomena they study. My subjectivity in the programme will have impacted my research. I had worked with the programme and was already interested in the questions about improving its quality. I noticed the gaps and had ideas about the problems, the stakeholders’ needs, and what changes were expected.

I also acknowledge that due to the collaborative nature of the qualitative research process, the knowledge created subtly changed my view. I have recognised that my views might affect the data collection and adopted strategies to maintain rigour in the study (see section 4.10). I documented the addition of new knowledge from my audio recordings, FGD transcripts, reflective journal, AUT’s progress reports, older drafts, and supervision minutes.

The CRs spoke a mixed language of Hindi, Punjabi, and Himachali, with some English words. In a few instances, it was challenging to be confident that I understood what they were saying. However, AI required that I check multiple times that I understood what they meant. I then translated the data as closely as possible to document what they wanted to convey. This prevented me from assuming what they meant, which was necessary for maintaining the rigour of research.

AI originated from management studies and aimed to improve organisational behaviour /change agenda (Watkins, Dewar, and Kennedy, 2016). AI seeks to build a shared vision by focusing on an organisation’s positive aspects, emphasising the importance of developing a shared meaning, especially data collection, analysis and reporting leading to organisational change. The AI literature does not clearly define the role of the researcher in data analysis. My role as the researcher, and the process of AI analysis, evolved, based on what I was learning in the field. This complexity reflects a key aspect of participatory analysis in the context of AI, where the emphasis is not merely on conventional data analysis by researchers, but on the active involvement of participants as agents of change (Watkins, Dewar, and Kennedy, 2016). In this process, participants were encouraged to articulate organizational or programmatic challenges and collaboratively explore potential solutions.

Though the data gathered from the focus group discussions (FGDs) and interviews were extensive, amounting to 33 hours of recordings, however, within the 4D framework of Appreciative Inquiry (AI)-based data collection, most data originated from the 'Discovery' phase. The other three stages – 'Dream', 'Design', and 'Destiny' – contributed less data. The focus on the 'Discovery' phase, which primarily involves problem identification, can be attributed to the participants’ immediate recognition and articulation of issues, whereas envisioning solutions may have been more challenging at this early stage. Ideally, a longer engagement with AI, providing more opportunities for iterative discussions with participants, might have facilitated a more balanced data collection across all four stages. However, the constraints of the PhD timeline limited this possibility. In adapting the AI methodology to these time constraints, the research acknowledged the predominance of the 'Discovery' phase, underscoring the participatory nature of the analysis where participants' insights were central to understanding and addressing the issues within the HIV counselling program.

I acknowledge that AI aims to support constructive change for the benefit of CRs. To some extent, that could not be achieved due to the programme’s resource constraints and several participants’ migratory lifestyles. However, I witnessed that the CRs and the staff felt a positive change initiated by the process of AI. For instance, participants acknowledged that it was the first time someone listened to their difficulties and perspectives on HIV counselling.

4.14. Summary

While taking steps towards improving the programme, it is essential to understand that the decision-makers in such a bureaucratic structure rarely know how these services can be improved. Being occupied with several programme-related activities, they are less informed about the programme challenges and easily overlook the need for improvement. Certain activities needed appreciation and replication in present times. AI was the methodology that helped me conduct such a positive inquiry, where the CRs were given a space to present their views. FGDs encouraged participants to share what they believed worked well in the system. These perspectives inspired ideas to improve the programme delivered in the Una district in the actual fieldwork. These views would help construct a bridge for the passage of CRs’ views to improve policies and determine their programme’s destiny. More positive and appreciative responses were received when the importance of AI was re-emphasised. My role as a facilitator and the rapport I had with the CRs allowed maximum participation. I look forward to sending the final thesis to the district authorities and providing a result summary as a future resource to FCS and NGOs associated with HRGs and the Una district HIV programme authorities so they may use it to inform future HIV counselling policies.

CHAPTER V – DISCOVERING ORGANISATIONAL FACTORS

MANAGEMENT AND ORGANISATIONAL FACTORS IMPACTING PROGRAMME EFFECTIVENESS

We need to break the silence, banish the stigma and
discrimination and ensure total inclusiveness within
the struggle against AIDS.
Nelson Mandela (2000)

5.1. Introduction

The results of this study have been structured using the 4Ds framework described in the previous chapter. However, it was found that most of the discussion in the focus groups centred on the problems and issues faced by the CRs. There was much less discussion on the final stages of the framework—dream, design, and destiny. Hence, the discovery sections have been divided into two chapters—Discovery I and II. Chapter 5 focuses on programme effectiveness from the perspective of management and organisational factors, and Chapter 6 captures programme effectiveness from a client centred social and cultural focus. In Chapter 7, dream, design, and destiny are a more interpretive discussion of the data.

AI proposes a participative approach in fieldwork where data collection and analysis are inseparable, and encourages a collaborative exercise with participants (Mace et al., 2014). This study utilised a participatory research approach constructed upon a critical worldview to analyse the data. This approach enabled the creation of shared meaning and an organic move towards building a shared vision (Cooperrider and Whitney, 2005). The 4D phases of AI aim to inquire into and appreciate what gives life to people: what matters to them and how they experience and understand it. These perspectives contribute to a greater appreciation of the organisation or programme (Carter, 2006). As a change-oriented team, the coresearchers, HRGs and FCS, collectively determined what they wished to use through a process of sharing, generating ideas and images for the future (Bushe and Pranjpey, 2015) to improve the programme.

5.2. Management and Organisational Factors Impacting HIV Counselling

Management and organisational factors act as barriers or facilitators to an individual's HIV prevention behaviours and their decision to access counselling services, thus having a major impact on programme effectiveness (O'Leary and Martins, 2000). Perhaps the understanding of why services are sometimes ineffective has shifted from attributing it to individual high-risk behaviours to a wide range of relevant factors. These include management organisation, and social factors, such as physical, socio-cultural, organisational, community, financial, and policy aspects of the environment that impede or facilitate efforts to avoid HIV infection (Gupta et al., 2018). In this thesis, the term management and organisational factor relates to the organisational and implementation aspects of the programme, while social factors include sociocultural and community level aspects of the programme.

A fundamental goal of an HIV counselling programme is to change the behaviour that puts individuals at risk of infection. The interaction with management and organisational factors highly influences HRG behaviours, making them vulnerable to HIV (Gupta et al., 2018). This section presents the interconnection of HRG vulnerabilities with the management and organisational factors that facilitate or impede HIV transmission and shape programme effectiveness.

5.2.1. Social Impact of Lack of Privacy at the Counselling Centre

There were significant privacy issues with the programme delivered at the district. The construction of counselling rooms did not support privacy, and these issues were not corrected even after several requests, as described by a CR:

> *I have requested them to make the glass opaque. I also told them that they should remove the chicken mesh surrounding that window because it permitted the sound from inside to go outside. I repeatedly advise the staff to close the corridor doors. I am often unable to completely close counselling room doors as culturally it is not advised to close the doors of the room where you are sitting with the female alone.* – Natu, FCS

The counselling centre was in the main building of the Una district hospital and next to the testing labs. The walls were not soundproof, and transparent glass allowed people to see the clients. No clear signboards or indications directed the clients to the counselling room, which put HRG clients in considerable inconvenience and deterred them from revisiting.

The conditions at the HIV counselling centre at district Una were not compliant with programme standards. The guidelines advise that the counselling room should be at least 225sq.ft. with adequate ventilation and audio-visual privacy. It should be furnished with a desk and chair for the counsellor, another 10–15 chairs for group counselling sessions, a lockable filing cabinet for keeping records, and a desktop computer with a computer table along with UPS, printer, and functional internet connectivity (NACO, 2016a).

The centre was dark, damp, not well furnished, lacked an operational computer with internet and printer, and had no secure cabinets to store client information. This arrangement resulted in breach of confidentiality and was a clear violation of the programme guidelines for counselling, Outsiders, other than the client and counsellor, were able to hear the client-counsellor interaction in progress. A FCS explained the impact when there was lack of privacy:

> *No one should be permitted to come into my room or to the lab during the counselling session. Not even my friends or any other staff at the hospital should be allowed. The client did not talk to me at that time, and my time was wasted.* – Natu, FCS

Such experiences discouraged the clients from getting tested or returning to the counselling centre to collect their test results. The clients faced discomfort from this breach and avoided sharing personal information with the counsellor, especially those related to their high-risk behaviour.

Most HRGs wore regular rather than flash clothing to avoid stares. Some hid their connection with NGOs due to fear of social discrimination and separation that could lower their dignity and lead to the possible loss of social roles. However, specific actions by hospital staff exposed these clients to discrimination and breached their confidentiality:

> *The centre is close to the general lab. Many staff members are also curious about the test results of others. They sometimes even peek into the counsellor's room or sift through files to see any records that say that the person was positive. Even sometimes, my friends come in, and they are discriminated against for being HIV positive.* – Natu, FCS

Una does not follow a fully digitised system for patient medical records. Therefore, the FCS sometimes faced a challenge to securely share information with other staff members about the HIV status of the client who may visit other hospital departments. Therefore, it was a regular practice by the hospital staff not related to HIV counselling and testing to peek into the counsellor's room and sift through the patient records to identify if the patient was HIV positive, thus taking extra caution while treating.

> *We have been told by the office to put an indication on the files that denotes a client is HIV positive. In the last meeting with the state, we were told that if you get a positive and he is admitted, please put an indication or a star mark on his file so that the staff knows about it.* – Natu, FCS

Some staff even put a "dot" on the clients' files based on the HIV status of the client, adding more to unfair behaviour towards HRGs. Although this alerted staff to clients' HIV status, it further enhanced the discriminatory behaviours towards HRGs and PLHIVs as they were treated differently from the other patients.

When HRGs visited counselling centres, they did not get a private space to discuss their issues. Most of the time, there was a crowd at the door of the counselling room and testing lab; therefore, the chances of people overhearing private conversations were high:

> *Some even roam around the counselling room to hear if the person was tested positive. It is easier to guess if the person starts crying in shame or denial, after getting a positive result.* – Natu, FCS

Because of the lack of a separate waiting area for HIV counselling and testing, HRG clients had to use the seats available to accommodate waiting clients or be a part of the queue awaiting testing at the labs. Many clients preferred to stand and wait in front of the counselling room for their turn, ensuring the counsellor summoned them on a first come, first-serve basis. According to one CR:

> *There is always a crowd looking at the people coming in and going out of the centre. People notice the people trying to find the counselling centre, even at the reception. They notice if a NGO worker accompanies someone to the centre. They are curious about the NGO and want to know the type of HRG who comes in.*
> – Natu, FCS

Many HRG clients did not get registered to the programme and were counselled as members of the public. They were afraid that when NGO staff accompanied clients to the centre, members of the public might detect that client was HIV positive. For example, a FSW CR shared that a person waiting in the hospital registration queue denoted her as a "sex worker" when he saw the accompanying NGO staff. The company of an NGO staff raised suspicions that the person could be HIV positive, which may have been a deterrent to seeking counselling.

5.2.2. Delays Faced by HRGs When Attending Counselling Programme

HRG CRs indicated that compared to other walk-in clients, they had to visit more offices and wait for long hours for HIV treatment and care. Some HRGs were forced to leave without treatment. This discriminatory practice of limited access to health care at the Una district hospital sometimes made HRGs reluctant to visit hospital for counselling, testing, or treatment, calling it a waste of time:

> *Visiting a hospital is a total time waste. Going to the hospital, getting registered, tested, and medication means one entire day is wasted, sometimes more. If we request to speed it up, they ask us to shut up, saying they know better.* – Chela, IDU

Some HRG clients shared experiences of lack of proper counselling, testing without consent, difficulties in seeking admission, and results being disclosed to close relatives; the latter being a frequent practice in Indian hospitals believed to protect the patient from possible emotional stress (Stevelink, van Brakel and Augustine, 2011). These HRGs added that the registration process for getting HIV treatment and other healthcare services through the programme involved lengthy documentation. Some HRGs reported that doctors and nurses declined to serve them after they were identified as HIV positive, delaying the process further.

Many times, HRGs had to wait for long hours resulting in many low-skilled labourers losing their regular income, making them more vulnerable to poverty. These HRGs were primarily from the lower economic strata and relied on their daily income for food and other expenses. While the treatment was free or subsidised for HRGs at the district hospital, to avoid delays some HRGs sometimes sought private treatment for ailments. Some HRGs stated that they paid out of pocket for treating abscesses due to injecting drugs, managing withdrawal symptoms, or other associated illnesses.

5.2.3. Counselling Service Only Available at Inconvenient Times

One critical management and organisational factor influencing the decision to join counselling and testing was that the services were not open during convenient hours. The centre only operated during business hours and not in the evenings. Often this was inconvenient for HRGs as the opening hours of the counselling services did not accommodate their work lives:

> *HRGs must come to the hospital to get counselled and tested, and the hospital hours are the same as the HRG work hours. The counselling and testing centres are closed in the evening, and even the NGOs are closed. It is even worse in winters, there are long queues for testing, and the lab closes by mid-day. Earlier, there used to be mobile counselling centres used to visit hotspots, but now they have been stopped.* – Yog, FCS

Many HRGs did not have the freedom or authority to visit services at their will. They engaged in low-skilled labour, and the stability of their households largely depended on their daily work. They had precarious work situations, and their livelihoods could be at risk in case of absenteeism or seen visiting the counselling centre.

With the spread of HIV among HRGs working in low-skilled labour, many households faced significant financial debts due to social exclusion, loss of jobs, and illness before getting registered under the HIV control programme. These debts further delayed their access to counselling, testing, and treatment as HRGs had to spend out of pocket to travel to get the services. As they had poor financial security, even a few days leave from work could pull their household to poverty. Further, when HRGs return to their hometowns due to job loss, HIV can be transmitted across borders. Although there was a process to transfer their registrations to a treatment centre in a different city, this was of limited value in the case of circular labour migrants, as it failed to accommodate the erratic and unstable nature of migrant work (Rai et al., 2017).

5.2.4. Inadequate Provision of Mental Health Support Within the Programme

The CRs reported having experienced stigma and discrimination in their lives but did not indicate seeking any mental health support apart from attending HIV counselling sessions. The discussions with young MSM participants had no reference to in-depth conversations between counsellors and HRGs. The counselling sessions never dwelt on narratives.

> *We do not have any such concept of mental health counselling. We are only giving them advice for safe sex behaviour. We have not motivated them for leaving unsafe practices altogether. Counselling talks about behaviour change. Behaviour does not only change with safe behaviour. There is always a chance that worse can happen. Every time it is not necessary that we are doing safe activities always. Our counselling is more applicable to conveying about the test and its importance, about safe practice. It is not about telling them about the harmful effects of such action and why they should stop doing them. We are exposing them to knowledge without context.* – Hira, FCS

Counselling sessions did not address historical discrimination and its mental health impacts. As noted, the sessions were brief and did not incorporate mental health counselling. Although the counselling guidelines stated that psychosocial support should be provided to HRGs wherever necessary, it was not a part of regular HIV counselling practice in Una. The services followed a blanketed approach for counselling of all HRGs.

The stories from FGDs involved unique experiences of trauma with mental health impacts. Although these stories were shared during FGDs, a recurrent observation was that these stories were not addressed during counselling sessions. For instance, a group of young MSM shared their views about the programme but feared disclosing their sexual identities to their families. Another CR reported imprisonment due to high-risk behaviour and being sodomised at an early age:

> *A middle-aged man sodomised me. I was 15 at that time. The middle-aged man assured me that we would get married someday. I never knew whether I was heterosexual or homosexual, but I became less interested in women after this incident.* – Aby, MSM

On asking the young MSM whether he discussed the above experience with a counsellor, he nodded in denial. An NGO staff who was not a counsellor knew about these stories. She added that among several reasons young MSM engage in high-risk behaviour, poverty was the main reason that pushed them to engage in unprotected anal sex for money. The CRs stated that HIV counselling should have a broader scope in providing mental health support to people at risk of HIV in Una and should not be merely limited to prevention advice.

From the IDUs' perspective, HIV counselling was limited to prevention advice and providing links with treatment. It did not provide mental health or other social supports to HRGs. There was rarely any private psychologist or mental health expert who could support them. The only mental health support available was at the de-addiction centre, which was in "deplorable condition". One CR commented, "*No one will ever want to go to these centres again. Your spirit will tremble on listening to their experiences and the tortures*". Furthermore, these experiences stemmed from self-harm and suicidal ideations in many IDUs, who then presented a total distrust in the purpose of attending counselling.

Bockting et al. (2016) stated that the reasons for inadequate counselling programmes in low- and middle-income countries were limited budgets for mental health, poor access to services, limited infrastructure, and lack of available mental health professionals or alternative support methods. Similarly, Wills and Holmes-Rovner (2006) stated that chronic exposure to mental health issues, combined with social stigma, prevents individuals from seeking support. Clients with mental issues often give more importance to the negative aspects of treatment, such as avoiding adverse treatment side effects, impacting their preferences for seeking support. Although laid down in counselling guidelines (NACO, 2016; WHO, 2007), the absence of psychosocial support in Una’s programme has an impact on the decision of HRGs to attend counselling.

5.2.5. Lack of Appreciation by Authorities for the NGOs

Some CRs working with the NGOs expressed a different perspective of the HIV counselling programme, which involved behaviour change of HRGs. The CRs who worked in NGOs believed the improvement of HRGs’ risk behaviour was impossible in a short counselling session delivered at the district counselling centre. The role of NGOs, as they mentioned, was not solely limited to getting HRGs registered to the programme. hey believed that their staff significantly contributed towards supporting HRGs to be protected from HIV and its complications. The NGOs were an integral part of the overall programme and implementation would be incomplete without NGOs’ community-level activities.

Some CRs were unsettled by the authorities’ lack of appreciation of NGOs’ efforts towards bringing changes in the risk behaviour of HRGs. A few complained that the authorities did not acknowledge NGOs’ contribution.

> *They demand a complete behaviour change of IDUs from the NGOs, which is impossible in this short time. When we bring an IDU, it should be recognised as an achievement of counselling. It takes effort to do so. He may not leave the drugs in a short time. He needs many sessions. The counsellor should give him more time. But the achievement of bringing the IDU is not recognised. We fill many forms, and there are several activities in the background that are not appreciated.* – Yog, FCS

Along with sharing a different understanding of the expectations from the programme, the CRs criticised the authorities for not appreciating their efforts. The discussions revealed that the district authorities did not recognise the breadth and complexity of the work done by FCS at the community level. According to a CR, the NGOs took efforts to transition non-HIV positive IDUs from injecting drugs to oral substitutes to decrease the IDUs likelihood of using an infected syringe and contracting HIV.

The CR further added that this required intensive communication and support to the clients; therefore, this activity should be considered an essential part of counselling. However, according to some CRs, the state neither recognised nor valued this activity. The state authorities did not require the NGOs to capture such events in their monthly reports where the behaviour change of IDUs was achieved by registering them into OST for the treatment of addiction. The authorities only considered those IDUs who continued OST as worth reporting. This reporting practice was contrasted by CRs presenting a significant mismatch, where the state's priority was on the briefer reporting. The reality of counselling where the FCS directly impacted the lives of their clients through attempted HIV prevention was neither appreciated by these authorities nor captured in their reports.

5.2.6. Lack of Trust by HRGs Due to Disrupted Continuity of Care

HRG clients discussed how trust was vital for successful HIV counselling services, which can be maintained through continuity of care. While distrust was a common theme for all HRGs, a pregnant mother's insight is central to the following discussion. The funding interruptions and staff turnover resulted in a lack of trust in some HRG groups towards the FCS. This loss of trust was witnessed among pregnant mothers from HRG communities who visited the centre as a part of their regular ANC. HIV counselling and testing were mandatory for pregnant women registered at public hospitals where the state implemented an HIV programme. Mother to child transmission of HIV was a significant reason for paediatric HIV infections in India, accounting for 12% of all new infections (NACO, 2016b). It can occur during pregnancy, delivery, or through breastfeeding. However, the pregnant women of Una attending the programme showed a lack of trust in the operations of FCS:

> *She was in the second month of pregnancy. They were giving HIV drugs free. I said to her not to worry, take medicine properly, and the situation will be better. She replied to me that many people like you come and go. Today you are here. Tomorrow you will go away from here. Finally, her sister had to involve convincing her.*
> – Kalyan, FCS

The staff turnover may be attributable to the interrupted flow of funding that hindered the continuum of care. These disruptions led to the HRGs' loss of trust in the operation of FCS even after considerable effort to persuade the pregnant women. The programme has been used to prevent the loss of treatment linkage for HIV positive mothers (NACO, 2013). However, it is challenging to convince HIV positive mothers not to breastfeed, as societal cultural practices and beliefs criticise mothers who do not breastfeed as shirking their maternal responsibilities (Vignarajah, 2004). Some pregnant women did not seek treatment because of the stigma and distress of testing positive, which further contributed to the difficulty of persuading them to receive a counselling session.

5.3. Ineffective Implementation of the Programme

The following section discusses the challenges faced in the implementation of the programme due to non-cooperation by hospital authorities, bureaucratic challenges in the flow of funds, ineffective reporting processes, inadequate adherence to programme guidelines, lack of state resources, and poor appreciation of HRGs' lives.

5.3.1. Non-Conformance to the Counselling Guidelines and High Workload

The counselling sessions conducted under the programme did not conform to the guidelines. As discussed in previous chapters, a standard counselling process is supposed to involve a pre- and post-test session of approximately 40-minutes in total

(CDC, 2001). It also advises giving clients sufficient time to consider their results and help them cope with emotions arising from the diagnosis of HIV infection (NACO, 2007a, 2016). However, the practice of HIV counselling in Una was different to national operational guidelines. According to a CR:

> *A counsellor should ideally deal with 8 to 10 clients in one day, as per standards, while we sometimes deal with 70-80 or more clients in one day at the Una counselling centre. There are 8-10 in the queue at all times. They are continuously coming. Counselling gets poorer because of such a workload. This is the burden of counselling. Our aim is only to get the testing done, and our work is done, another testing is done, and the work is over.* – Natu, FCS
>
> *To achieve target requirement of 400 to 500 or even more cases per month the daily workload for counselling and convincing them to do a test is too high. If it is low as 250, their faces will be sad, and they will ask – why so less!!!* – Hira, FCS

FGDs revealed that the number of clients coming for testing was so high that the counsellor could not even deliver a 5-minute pre-test counselling session to each client, let alone the 20-minute standard. The post-test counselling was not given recognition in reports. Only HIV test positive clients underwent a post-test counselling session to help them cope with the desolation due to their positive test results. However, these were also short as per the standards. The CRs further added that the state officials discouraged counsellors from spending time on the post-test counselling for clients with negative test results, considering them irrelevant. In most cases with negative HIV test results, the results were not conveyed to the clients unless they came back for results. However, post-test counselling was marked as completed for all clients even without meeting them for reports.

5.3.2. Absence of Gender Matching and High Workload

There was no female HIV counsellor at the district counselling centre, despite many women attending for HIV tests. The social construction of Indian society does not allow a female and male to interact in a closed room in the absence of another female; thus, the counsellor must keep the door partly open for moral correctness. However, as the HIV programme budget only funded one regular counsellor for the Una district, the male counsellor counselled both male and female clients.

> *The workload is too high. There is no female counsellor. No one to replace the male counsellor if he goes on leave. Imagine if a peer educator brings someone from a far-off village, for getting counselled and tested, they will be troubled.* – Hira, community worker

The HIV counsellor counselled 50 clients on an average day, with the highest count of 90 individuals counselled on the busiest day by a single, solo district-level counsellor. This count included clients from all genders, HRG groups, and the general populace. The guidelines recommend appointing an additional counsellor where more than 500 individuals got counselled in a month or when the clients demand a counsellor of the other gender (NACO, 2016a). However, the state did not fulfil any such requirements for additional workforce even after repeated demands from the clients, showing a gross breach of standards. Studies have also reported privacy issues and higher workloads at other HIV counselling and testing centres (Chellaiyan, Raut and Khokhar, 2018). Even the peer educators, who are HRG community members supporting NGOs and impart health-enhancing behaviour change to other HRGs, were far fewer in number, while those working were underpaid.

5.3.3. Reporting Issues Related to the Programme

The CRs stated that the reporting system followed by the programme at Una district was labour intensive, time-consuming, and ineffective. As previously discussed, the programme was managed by the Una DAPCU, a subsidiary of Himachal Pradesh SACS which utilised the district hospital building and resources and contracted local NGOs for delivering its services. The FCS, who consisted of district-level and NGO-level staff working under the programme, submitted monthly performance reports to both district and state. The FCS primarily criticised this dual reporting system:

> *We send reports to both. There are piles of reports that we send to them every month as a registered post. It is not cheap. We also send emails. Sometimes they demand photographs of NGO activities, also not cheap to take. But what is the use of sending them when they will come back to us again, especially just before the end of the business? It usually happens on the busiest day of the week. Often, the staff is engaged, and the programme manager faces difficulty pulling the different reports together.* – Hira, FCS

The dual reporting system resulted in missed communications, which resulted in repeated reporting, thus further increasing the staff’s workload. Only a few reports were submitted via an online central health management information system specific to hospital employees. Most reports were paper-based, although some were offline computer-based. Both systems required time and resources. The monthly progress report on community activities was emailed and posted to both recipients. However, the CRs observed that these reports were not examined or stored, even after being sent by the deadline.

CRs reported that the officials missed the hard copies that were posted or emailed to the state authorities; therefore, the NGOs had to resend them with additional postal costs. This casual approach by the state-level staff resulted in wastage of resources in the form of NGO staff time, reprints, and postage. Also, staff were not reimbursed. Additionally, many staff members lacked good IT skills and, therefore, spent more time in compiling reports into hardbound registers, as noted below:

> *The referrals slips are entered from the hospital, then to the outreach workers registers, the counsellor’s registers, and the NGO’s file records. There is much repetition of the entries. The amount of documentation and making these registers is not cheap. There is no IT system to record them in one place. Making soft copies will be a clever idea to solve this problem, but we are not good with computers.* – Hira, FCS

The CRs acknowledged that they lacked both knowledge and resources for IT-based data entry and report compilation. Much of their time was wasted in duplicating entries into different client registers, and repeated reports to SACS was a significant challenge. The FCS indicated that six client register notebooks had to be maintained to comply with programme requirements. Some standard registers for the NGOs were the counsellor's register, peer educator's register, outreach worker's register, HRG clients' register. For the district, registers included pre- and post-counselling, testing, Lab, ANC, and HRG and so on. The CRs working with these NGOs reported that state authorities were unwilling to change to computer-aided measures of database management. The district authorities did not have the necessary IT support to enable it.

CRs further alleged that both NGOs and district counselling centres were not provided with the requisite IT support. There was a lack of operational computers or an internet connection to upload data online or to email reports. The available computers were non-functional for months, and not repaired even after several complaints to the authorities. The Wi-Fi adapters were ineffective for communication with the counselling centre. The staff were later directed to use a local cyber cafe to send these reports, which some CRs believed was unethical, ignored the privacy of data, and disrespected the sensitivity of the information it contained.

The computers allotted to the NGOs in the previous round of the HIV programme were still awaiting delivery. Even after several reminders to the state regarding non-functional computers and the unavailability of the internet, no action was taken. CRs added that the state had overlooked the reporting requisites of the programme, such as IT and database management techniques, before its implementation, and these issues were easily avoidable.

> *There is total mismanagement. Reports are framed—their genuineness questionable. The NGOs have to bend to the demands of the authorities. They only get the project if they bribe the authorities. The staff are exploited and do not make a case (court*

> *case) against the authorities. They fear that their funding with stop. They don't want to get in trouble with the authorities. They want more projects in the future, and we do not want to be blacklisted.* – Hira, FCS

Some CRs raised questions about the genuineness of reports. They stated that the reports did not depict the ground reality and were framed based on how the district wanted to report its progress to the state. The CRs referred to it as "a total mismanagement". These reports had the list of clients and the services obtained from the NGOs that, on their basis, would help the NGOs claim funds. Their concern was that the NGOs had to obey these demands as they feared that their contract would be discontinued. Some CRs stated that many of these projects were allocated after bribing the authorities, and any complaints against the authorities may lead to them being blacklisted from future projects.

5.3.4. Counselling and Testing of Ineligible Clients for Achieving Targets

The CRs employed by the programme criticised the NGO staff for referring ineligible clients to the programme. They accused NGO staff of having questionable intentions of achieving their monthly targets by improper means.

> *Many clients do not know why they have been brought in. They are not told what the test is about. A client said that she thought the test was for her knee pain. They are brought to achieve their monthly targets of testing. After counselling, they deny giving a blood sample. Those who give blood complain that we took so much blood out of them, calling the staff 'blood seller'.* – Natu, FCS

Accurate data collection and reporting depends on the standardised and integrated recording and reporting systems crucial for running any PHP. However, FGDs revealed that some staff members followed dubious practices to increase numbers. The CRs observed that the state officials were more concerned about the increase in client registrations and clients put on treatment, which were the district's key performance indicators (KPIs), overlooking the quality of counselling.

5.3.5. Lack of Transparency in the Distribution of Funds

The AI discussions revealed that the CRs witnessed a lack of transparency in finances and distribution of funds related to the programme at higher levels. CRs alleged that the authorities at district and state levels conducted unclear financial transactions. Frontline workers criticised these officials for their ambiguity in financial transactions and their unclear accounts. Some even alleged that many NGO officials who accepted the project funds at the start never participated in the project activities. A CR added:

> *We were called for counselling training at Tanda; Dr XYZ was the joint director at that time. He said that we had given you money 14000 INR (320 NZD). You have to cover 20 schools and conduct HIV-TB awareness activities in these schools. Imagine conducting one school in 700 INR (16 NZD). I asked him, now you have made us thieves too. He asks me why. I answered, obviously, at the end of the day, I would expect to get at least 2000 INR (45 NZD) for our allowances, and we will have to take that money out of the amount you give.* – Unnat, FCS

A CR reported an incident when a school-based HIV awareness campaign received partial funding from the district, not enough to fulfil its financial requirements. The allocated funding was only one-fourth of what a school-based awareness campaign should have received. Consequently, the school was unable to complete the campaign and the state had to reallocate more funds and redo the campaign. This example portrayed mismanagement and wastage of time and resources.

The AI experiences further revealed that improper dissemination of funds was a significant issue with programme implementation. The funds for salaries, travel expenses, daily allowances, and accommodation expenses did not percolate efficiently from the state to the district and further to the NGOs. There was a mismatch between what was promised to the district employees and what was paid. Conspiring with taxi companies and hoteliers were common during travels for training where fake bills were claimed to reimburse more money than what was spent. Some hotels were owned by government medical officers where the trainees were forced to stay.

The CRs further added that the wages and other allowances paid to employees working at the same position at the state were remarkably higher than those who worked at the district level. More influential and better-connected employees got better employment locations closer to big cities. Although the HIV programme had an important role to play for the community, it ignored effective measures of unbiased transfer of funds and resources to the lower positions.

> *WHO team came for auditing, and we were told to contribute money for their expenses. Imagine that a WHO team coming into our area has not brought their expenses with them. I do not think this is possible. In reality, WHO might be paying them, then why are we paying? Moreover, in the end, everything boils down to finances.* – Hira, FCS

Some CRs shared their concern about the faulty internal auditing process for the NGOs, which affected the completeness of annual reports. These CRs indicated that the auditing system was flawed. For reviewing annual reports, many NGOs appointed auditors internally. The CRs stated that they believed these auditors were paid incentives for making desirable audit reports that pleased higher officials so that the project funding for the NGO could be continued.

> *Bill Gates sends the money of Rs. 3 crores (USD 600,000) to Una to get the HIV programme running. The project head takes a cut for him. The scenario is the same everywhere, whether it is Himachal Pradesh or Punjab. Everyone is looking for some profit out of this programme, the deep-seated corruption. It is the same in every state.* – Natu, FCS

The CRs further stated they believed the Una district HIV prevention and control programme received high sums for the programme activities while only a part was allocated appropriately. One CR from the HRG community made a powerful observation that "*only 1% of funds were put for right use while rest was consumed in bribing, corruption, and adulations*" (Avin). According to some CRs, this created mistrust regarding whether funds flowed into programme activities.

CRs stated that the recruitment and wage increments were not conducted in a fair manner. Some CRs had witnessed intense lobbying and preferential recruitment based on associations of the candidate with state officials or with the political elites. An incident was shared when the candidate who ranked higher in the qualifying exam was not recruited while the one associated with a state-level bureaucrat was recruited. Though such biased decisions resulted in lawsuits against the state, most were fruitless as the state had money to defend and power to influence tribunals. Similar mismanagement was reported in the recruitment of employees at the district level, where a practice of nepotism was observed.

To summarise, the organisational and management factors impacting the programme for HRGs included organisational challenges due to lack of privacy issues and certain discriminatory practices by hospital staff. Other issues related to the organisational structure were long waiting hours for counselling, non-consideration of HRG demands for gender-matched counselling, and the programme's inflexibility in providing services at HRGs' convenience. At the same time, the implementation challenges included a limited workforce, inadequate compliance to programme guidelines and lack of transparency in processes.

5.4. Summary

This chapter focused on the findings from the AI Discovery phase, reflecting on the HIV counselling related experiences and perspectives of CRs and how they impacted the programme outcomes. The CRs shared ideas on how counselling was understood and what were the barriers for its effective delivery. The chapter began with a section on organisational and management factors and implementation challenges related to the programme in Una. The sections discussed relevant organisational and management factors that influenced HRGs’ participation in counselling. In this chapter, the impact of these factors was discussed as shared by the AI experiences of three key HRG groups.

As the population of Una is expanding, these impacts may not readily reflect in the programme outputs. However, they will affect the lives of these HRG CRs who did not get an opportunity to even imagine how a counselling programme should look like due to their lack of positive experiences from the programme and the systemic bias for being a part of the programme.

In the next chapter, analysis of this participatory research further reveals broader emergent themes around social barriers for HRGs to get counselled in general, followed by specific sub-sections on each significant HRG group relevant to Una district—IDUs, MSM, and FSWs.

CHAPTER VI – DISCOVERING SOCIAL FACTORS

PROGRAMME EFFECTIVENESS THROUGH THE LENS OF HRG CLIENTS OF HIV COUNSELLING IN UNA

6.1. Introduction

The previous chapter revealed the challenges associated with the management and organisation that impacted on programme effectiveness. They effected the decision of HRGs to seek counselling, thereby increasing their vulnerability to HIV infection. The CRs presented how these factors degraded the quality of counselling sessions and lowered HRGs' trust in the programme, while also lowering the FCS's trust in the system. For instance, the HRGs' fear of HIV/AIDS-related stigma, discrimination, social abandonment discouraged them from seeking HIV counselling services, forcing them to prefer a more private lifestyle (Medley et al., 2004). The following section discusses these social factors in the context of stigma, discrimination, and social abandonment of HRGs, and how the incomplete understandings of their identities and needs act as inhibitors to their decision to seek counselling.

6.2. Stigma, Discrimination, and Social Exclusion as Common Barriers

Almost all HRG CRs and some FCS had experienced stigma and discrimination in Una; much greater than the reported state and national figures (NACO, 2015b). A third of all Una HRGs reported experiences of social exclusion, mainly related to stigma related to unemployment, delays in health care access, and abandonment from family and society (NACO, 2015b). However, these issues, reported via a national survey, have never been researched further to know the reasons behind such high numbers.

Many HRG CRs shared that the hospital staff discriminated against them based on their appearance, HIV status, and overt behaviour. Therefore, these HRGs disliked going to the hospital. For instance, the *baba*-IDUs described a range of deterring factors to the programme across personal, interpersonal, and organisational and management categories. A prominent factor was around interpersonal communications with the hospital staff. The counselling related experiences of stigma and discrimination, and previous unpleasant experiences at the hospitals and NGOs during treatment of addiction, were the most common.

At the same time, some organisational reasons also emerged, such as stigma and discrimination, unavailability of effective OST and rehabilitation facilities, and lengthy documentation requirements for getting registered under the programme. The factors associated with the experiences of stigma and discrimination were common across all HRG groups. However, some factors were unique, especially those related to religion, culture, and support systems outside the boundaries of the programme. These factors are discussed in detail here.

6.2.1. Rudeness and Misbehaviour by Hospital Staff

The impact of AIDS-related discrimination and stigmatisation at the Una HIV counselling centre can be seen through the personal testimonies of HRGs. These clients experienced disrespectful and offensive behaviour by the hospital staff, which severely discouraged them from attending counselling sessions.

> *I do not like to go to the hospital. The staff is rude, and they misbehave. They consider us as animals. They treat us differently than other patients. Once, they used derogatory words and made me sit in the corner for hours.* – Maharaj, IDU

HRGs' vulnerabilities were increased when these behaviours robbed them of their right to safety and dignity, as they were no longer willing to participate in the programme. Most IDUs did not trust the public health services and indicated that they were unfairly treated by the hospital staff when requesting medical treatment or HIV testing. Some disclosed that nurses and other healthcare staff referred to them in a demeaning manner, calling them animal names, and asked them to sit in the corner for a long time. Such derision was a usual affair for the *baba* men due to their unkempt looks.

MSM also experienced stigma from hospital staff due to their feminine gestures, which were wrongly associated with the stereotypes of HTG people, a highly stigmatised group and not even considered existent in the district. The hospital staff often discriminated against them in front of the general population, making them feel powerless in front of society and staff. Hence, many MSM preferred to keep their identities hidden, making it difficult for FCS to distinguish them from the general population. Such treatment towards HRGs is the norm in society. The healthcare staff are expected to be supportive and an effective the public health system could contribute to breaking this norm. However, their behaviour was also contributing towards a wider issue of societal discrimination against HRGs.

6.2.2. Social Exclusion and Failure of Programme Adherence Among IDUs

The social inclusion strategy for the Indian HIV programme is that it includes all HRG groups (NACO, 2012). Protecting and promoting the human rights of these vulnerable groups and empowering them has been considered vital to prevent the spread of HIV globally (Decker et al., 2015). Although the programme's vision is to treat HRGs with dignity and support them to claim their rights (Decker et al., 2015; NACO, 2016a), these strategies were not effectively implemented in the Una district. Instead of strategies for vulnerability reduction, the CRs shared their experiences of social exclusion, prominently observed in FGDs with most IDUs. The IDUs revealed experiences of social exclusion and the importance of the ineffective application of such strategies. The MSM and FSWs did not talk much about being socially excluded as they found other issues more prominent to discuss. They mostly lived with their families, while most IDUs left homes as their lives revolved around getting the next fix.

> *Whether it is a male or female if positive, society looks down on them. They will look at us [IDUs] thinking that immoral behaviour was involved. They exclude us thinking we are dirty. They forget the other three reasons for HIV. They forget that sex is the least probable cause of HIV compared to the other three.* – Avi, IDU

The above quote was shared by a non-*baba*-IDU who felt socially excluded as HIV was considered a social taboo. It shows an intersection of reasons for social exclusion. Although socially excluded, the *baba*-IDUs considered them separate to other HRGs who participated in sexual activities. AI experiences from HRGs revealed that the association with HIV lead to social exclusion experienced in various ways such as unemployment, poverty, prejudice, exposure to risky environments, inhibited access to healthcare, and abandonment from family and society. The conditions were worsened by their feelings of hopelessness, sadness, and suicide, and their reluctance to attend HIV counselling.

Research has identified a strong connection between drug addiction and social exclusion (Rossow, 2001; Schafer, 2011), which was mainly associated with how society perceived IDUs. Some IDUs shared that they have experienced stigma where society has associated them with thefts and other petty crimes. In some events, people have reported IDUs for harming others, stealing, or robbing others to fund their habits. Some IDUs even harmed themselves by self-infliction or ingesting poisonous substitutes like sleeping pills, turpentine oil, anti-inflammatory ointments, or even cough syrups with a bronchodilator. Due to these historical events, the IDUs of Una were commonly detained by police officers.

IDUs disliked attending counselling as they were asked to stop taking drugs and even encouraged families to forcibly admit IDUs to the hospitals. Some families asked IDUs to move out of their houses. Those IDUs who returned home were threatened and even physically assaulted. During a relapse, non-hospitalised IDUs roamed around, looking for avenues to buy drugs. Many IDUs resorted to stealing or demanding money from their friends.

> *These drugs compelled me to run away from my family. My family wanted me to stop drugs and stop stealing for drugs. I was in lock-up for a few days and then at the addiction treatment centre. But no one understood that the drugs were the only thought in my mind, and I was living for my addiction. Now my family members no longer care whether I am alive or dead. They do not want me to come back home.* – Chela, IDU

Unavailability of drugs was a typical affair for these IDUs due to lack of money, or family's control on their drug use while in police custody or at hospitals. Due to the unavailability of drugs, IDUs experienced withdrawal symptoms, including body pains, restlessness, reduced hunger and thirst, abdominal cramps, and uncontrolled anger (Kapoor, Kapoor and Sinha, 2007). They found that the oral OST provided by the programme was ineffective. Furthermore, the programme incapacity to satisfy their requirements resulted in a total distrust of IDUs for the purpose of attending counselling. Therefore, they rarely visited the NGOs to receive counselling and OST, presenting at the intersection of vulnerability and co-morbidity.

IDUs were often treated with bias, discrimination, and social exclusion, making them vulnerable to infection and the complications of non-adherence to treatment in the case of PLHIVs. Moreover, the issues of social exclusion were multi-dimensional and interlinked to a combination of other social factors, such as unemployment, lack of skills, low income, poor housing, and existing ill-health. In Una, social exclusion has significantly prevented HRGs from accessing HIV counselling services and has made them more vulnerable to HIV or complications of AIDS. As discussed earlier, OST and addiction treatment services run under the programme never served the physical and mental health needs of IDUs, leading to their non-attendance to the programme. The below quote adds the social exclusion perspective to this discussion. It shows the helplessness of an addict and his enslavement to the addiction, which has affected his mental health and social support.

> *I don't have a family; there is no one to support me or take care of me. I have been left astray and craving more drugs. Some days I do not find my fix, maybe no money or no friends around, I spend days roaming around in search of it. During days I get diverted, talking to people, roaming around. But the nights are unforgiving, with no one to talk to. I twist and turn in pain and anger as if I were a fish taken out of the water*. – Chela, IDU

Like any individual avoiding social exclusion, IDUs tend to hide from society and deny the possibility of infection. Such conduct results in other exclusionary impacts and effects on the long-term health of IDUs. Social exclusion exacerbated the sufferings of IDUs, for which counselling proved inadequate. Some CRs shared their experiences of social abandonment worsening their suffering from a relapse. These are reasons for a programme that recognised HIV as a social exclusion issue, indicating the intersection of vulnerability and co-morbidity due to HIV. Even seasoned IDUs discouraged the newer IDUs from using drugs, giving examples of their sufferings. While IDUS were isolated, there were informal supports within the IDU community where food, money, and shelter were sometimes supplied. However, no IDU was interested in attending HIV counselling sessions. They believed it could not solve their issues of social abandonment.

6.2.3. Powerlessness Experienced by FSWs Rendered Counselling Useless

As a person who has lived experience in the conservative Indian society and work experiences with the programme, I acknowledge that these factors make the counselling of FSWs far more complex. The Indian gender-based relationships present a typical unequal power in most spheres of a woman's life where the male dominates and the female subordinates (Esteve-Volart, 2004). Even though the FSWs wished to practice safe sex as advocated through counselling, several FSWs had to agree to the male customer’s demands for unprotected sex. This critical social construct was reflected in sex work. Due to poverty, and perhaps being a female, FSWs has no choice but to agree to the customer’s demands if they want money.

> *I tried my best to use condoms, but what can I do if they do not use them. I must agree to their demands as they pay money. I have often denied sex with those customers who were reluctant for protected sex, but it was terrible for me. I devised different ways to convince them, some agreed, but some didn’t.* – Sewa, FSW

The above excerpt shows the non-agreement of customers to safe sex even though it was promoted through counselling. Most FSWs wanted to practice safely. But some had little say in practising safe sex. The habit of obeying customers’ demands for unprotected sex made these FSWs more vulnerable to HIV infection. They reported that even though they bought condoms based on customer requirements, the FSWs experienced a reluctance from customers to use them. The counselling programme was unable to provide a solution for this issue.

In many cases, even the awareness of the impact of unsafe sex practices did not encourage men to use condoms. A CR further added *“I had seen them turning away when I insisted on using those*” (Reeku). A significant study observed a similar unwillingness among Indian customers to use condoms (Mallika and Katare, 2004) and indicated that the quality of condoms supplied by the support organisations based on the recommendations of the programme was not based on customer demands. The CRs thought that the counselling programme could provide them with better condoms which suited their customers’ demands.

Some CRs added that counselling programmes did not provide any help in their issues of domestic violence. Several FSWs had experienced physical violence, and the most common perpetrators were husband, boyfriend, or lover. This information coincided with national-level data, which reported that nearly half of FSWs had their husband as the perpetrator of physical violence:

> *I was suspicious that my partner went out to have sex with other women. I tried to confront her husband with my doubts, but he is an alcoholic and beats me. We used to fight a lot. He brought the HIV infection from outside. He gave it to me. They* [peer educators] *tried to caution me, but it was too late. We both got infected and were put on treatment.* – Sewa, FSW

Many women reported that they helplessly adopted sex work as a quick source of money. Some had a regular male partner, usually a husband, while they had casual or regular customers who paid them for sex work. Some husbands were alcoholics or drug addicts, and did not contribute to the household expenses. The women were left as the sole earners for their families and had to work extra hours for odd jobs besides the sex work. Many times, their busy schedule does not allow them to attend counselling sessions or get tested if they are willing to do so. Many FSWs were associated with the NGOs for seeking regular employments through the rehabilitation services under the programme that could help them get out of sex work. However, these employments are low paid and not enough to suffice their family's basic needs.

Poverty acts as a social determinant of health and exacerbates the vulnerability of sex workers to acquiring HIV. This is due to the power imbalances that exist within Una, where FSWs often have limited agency and control over their work conditions, including access to effective protective measures such as preferred condoms. This lack of power can be traced back to the systemic marginalisation of sex workers (Benoit and Shaver, 2006). Poverty-stricken FSWs are often forced into sex work as a means of survival, and not have the resources or negotiating power to insist on safe sex practices (Outshoorn, 2005). These power imbalances and systemic barriers leave sex workers unable to access counselling services or engage in risk-reduction behaviours (UNAIDS, 2017). The intersection of poverty and sex work perpetuates a vicious cycle of marginalisation, which further exacerbates the HIV risk for this population (Swendeman et al., 2015).

In conclusion, it is important to recognise the role that poverty plays in exacerbating the vulnerability of sex workers to HIV, and to address this issue through a lens of critical theory. This requires a systemic approach that addresses the root causes of poverty and the power imbalances that exist within the sex industry, and prioritises the health and rights of sex workers.

6.2.4. FSWs and MSM Feared Disclosure of Identities and Socially Exclusion

As discussed in previous sections, incomplete understanding of HRGs' individualities acted as a barrier to them accessing counselling services (Simoni et al., 2002). The programme was designed to prevent new infections or post-infection complications in HRG members beyond the boundaries of sexual orientation and social structures. HIV, however, was identified as a morally charged issue in Una, given its association with behaviours considered socially deviant such as drug use, homosexuality, and sex work.

Several HRGs hid their identity and HIV positivity due to fear of social exclusion which lead to non-disclosure of identity to the programme staff and not seeking counselling. This factor affected the decision of getting counselled for MSM and FSWs only, and not for IDUs. The following section discusses a social factor that affected some, but not all, HRG groups: fear of disclosure of identity.

Several MSM, from both urban and rural Una, intentionally avoided registering with the local NGOs. They were deterred from joining the programme as it involved the risk of disclosure of their sexual identity to their family members. The MSM, who were married to a female, had to juggle between their social gender role of a husband and their role of sexual partner to another man.

> *Before my marriage, I used to cross-dress as a female and performed folk dance dressed as a female in local gatherings. After performances, I was approached by men for sex. With some, I had sex. I never told my wife about my past experiences. I am*

> *bisexual now. I dislike having sex with my wife, but I have to do it as part of my role as a husband.* – Tichu, MSM

MSM struggled between their homosexual desires, their duties to continue family lines, and homophobia in the larger society. The stigma associated with homosexuality forced many MSM to hide their sexual preferences to avoid embarrassment and their families. Furthermore, these MSM feared being exposed if they went to counselling as they hid their identities.

Una is as conservative as wider northern India, with its residents constantly opposing homosexuality. The people in rural areas were less aware of the existence of homosexual practice around them, allowing the young MSM to maintain a hidden identity. This CR's narrative revealed that sexual relations with boys could be less detectable than with girls.

> *I feel safer with boys. People are less aware of what we do. They are not suspicious. I used to hang out with a girl. She was a minor. But her family got me prosecuted for having sex with a minor, and I had to be in police custody for months. Now, I dislike women. I prefer men. I know it is illegal, but police don't catch us unless they find us doing it.* – Nanny, MSM

MSM preferred being hidden as they did not want society to suspect, but many of them lacked a private place for their sexual practices. Several MSM stated that their families disagreed with their sexuality and getting involved in homosexual practices. This attitude resulted in MSM conducting homosexual practices in hidden corners of parks or uninhabited buildings instead of their residences, and that too without a condom. In the absence of a suitable venue, they cannot follow precautions or use lubrication in an effective manner, thus getting more exposed to HIV infection.

The MSM CRs found it safer to be involved in homosexual practices in rural Una than urban areas, as they could keep their identities and practices hidden from society. The CRs shared that the programme staff mainly recruited MSM from the urban Una out of convenience, while missing the rural areas of the district. Being aware of this recruitment practice, these men preferred to stay more in rural areas as they were less identified as MSM and less harassed by the police or general public.

The high prevalence of HIV infection among FSWs in India is not solely due to high-risk behaviour. It is also due to factors such as incomplete knowledge about prevention, poor socio-economic conditions, discrimination, and criminalisation of sex work and sex workers (MoHFW, 2016). In Una, these reasons were no different from those observed in the national level surveys. Several other reasons inhibited FSWs of Una from accessing the programme. The prominent one was fear of disclosure of their identity to programme staff.

During FGDs, IDUs and MSM were eager to share information and did not require any FCS input. In contrast, most FSWs were less vocal or forthcoming, probably because they feared disclosing their identity to the public. These FSWs were always accompanied by an FCS and relayed several FGD questions to their accompanying person rather than answering themselves. One FSW CR only agreed to share their experiences when reassured of respect and confidentiality during and after these discussions.

Indian FSWs experience widespread human rights violations, including violence, arrest, HIV-related stigma, and denial of social benefits and entitlements otherwise accessed by the general population (Ganju, Ramesh and Saggurti, 2016). These experiences were no different in Una:

> *The FSWs are scared to come up for counselling. The stigma with HIV tests and their discrimination is ingrained into the minds of the people. No one accepts FSWs with any dignity or an HIV positive with any respect. They do not even respect a counsellor who prevents people from HIV. On the other hand, their mentality tries to picture a counsellor working with FSW as an FSW. Their thinking will not change, or the whole picture needs to change, but that will not happen here.* – Kalyan, FCS

In Una, many FSWs do not participate in the programme to avoid the experiences of HIV related stigma due to discrimination from the disclosure of their identity. Some even deny their HIV positive status after getting infected. Others avoided being accompanied by an NGO worker or joining the queue for the general population to avoid the stigma of being categorised as a high-risk person. As noted in earlier sections, due to unlawful practices associated with sex work in some beauty parlours, women working as beauticians face societal stigma, a finding similar to Narendran's (2011) doctoral research on beauty parlours in India. Even FCS assisting FSWs had faced stigma by onlookers.

Several CRs reported that FSWs were victims of circumstances that later pushed them into sex work and exposed them to the risk of HIV infection. Some had to leave their hometown and come to Una to hide their identity. One CR shared a surprising finding of how she was lured into sex work and had to leave her city of residence:

> *My father died when I was young. There was no one to guide me. My lover promised me marriage, and I believed in him and trusted him blindly. But he was a dealer [pimp]. He sold me to others [people who sought sexual services] who forced me into sex work. My family and I had to leave our home, our town and come to Una looking for work. Now, I must do this work [sex work] to support my family.* – Kalini, FSW

The above narrative shows how vital it is for a sex worker to keep her identity hidden. During FGDs, some FSWs reported they were fearful if their HIV positive status was disclosed, and this fear was towards accessing the programme. The narrative also illustrated that "love" and seduction can act as powerful tools employed by dealers to lure young girls into sex work by playing on the vulnerabilities of these girls. While the dealers pretended to love these girls, they distorted their sense of right and wrong, convincing the girls to get involved in sex work (Kennedy et al., 2007). This statement indicated some rare incidences in Una. No brothels were identified during discussions where FSWs may find it easier to reveal their identities with customers seeking sexual favours.

Several FSWs who were diagnosed HIV positive or had faced direct stigma left Una and were no longer traceable. The FCS learned from colleagues in other cities that some were still selling sexual services even after being infected. They expressed that these FSWs were exposing their customers to the risk of contracting HIV. Other FSWs who had experienced real stigma were more open about their sex work and HIV status. A study reported that the FSWs who were no longer hidden showed improved quality of life (Thomas et al., 2005). However, the CRs noted no such observations. Some FSWs were successful in keeping their identities hidden and had not faced direct discrimination. Such findings have been considered favourable for the lives of HRGs as the real stigma is less compared to perceived stigma (Thomas et al., 2005).

In conclusion, HRGs' perspectives exposed a plethora of issues related to social construct that Una society had developed towards them. Yet, the counselling guidelines do not consider the social fibre and cultural diversities of Una.

6.2.5. Exploited MSM Peer Educators Less Supportive Towards the Programme

As discussed in earlier chapters, the NGOs have played a vital role in the operations of the programme in the Una district. Since the National Health Policy of 2002, NGOs have gained prominence in the Indian PHP for widening their scope and greater community reach (Sen, 2012). For the programme, these NGOs employ peer educators who are usually members of HRG communities who sensitise people to attend counselling and create awareness about HIV prevention (NACO, 2007b).

Many CRs shared that they were mistreated by the NGO staff. Some CRs, who also worked as peer educators, were unhappy with this mistreatment. A peer educator from the MSM community stated that it made him feel powerless. In turn, he sometimes discouraged other MSM from attending counselling sessions. The following statement showed the intimate nature of the MSM community and their disappointment regarding the counselling services.

> *I work as a peer, but I have to seek help from an NGO staff when it comes to reading and writing. He maintains the registers of my work. Outside work is under my control. I am connected with my community. He is not. If I clap loudly, I can bring in more than 50 MSM to the centre. He asks me to bring the clients to the NGOs, takes their phone numbers but never pays me for bringing them in. I call him. He never picks up the phone. I have helped him achieve his targets. I have to do it, or else he will not pay me my wages as a punishment. He said that I deserve this kind of behaviour. I want to remind them that if they disappoint me, I will tell my community not to come to the NGO anymore*. – Komu, MSM

The peer educators were HRGs who supported the outreach activities of the programme. The peer educators brought other HRG clients to the counselling centres and received a minimum wage on a per-client basis. The amount was just enough to compensate for travel and food. However, many peer educators complained that the NGO staff delayed their payments. This misconduct discouraged the peer educators from continuing their outreach efforts.

The peer educator CR reported that the NGO ignored his grievances. He added that the NGO staff took advantage of his lack of literacy and did not pay him his wages for several months. Consequently, he reported he would discourage other MSM from joining the programme, but he was worried that the NGO staff would punish him by delaying his future pay. He felt powerless due to such tyranny by the people in power. However, the NGO staff blamed the programme authorities for delaying payments to the programme:

> *Recently the NGO has stopped paying me. My family scolded me for not bringing any money after days of toiling. I had spent money for fieldwork out of pocket, which was never reimbursed. The staff used to talk nicely with me until he took the list of my contacts and then told me that the funds were not received. Later he rebuked me by saying, - you deserve such behaviour. Now he does not meet*

> *me or attend to my phone call. I fear that he spent my money on his friend's marriage. If I want, I can also make his life hell. I no longer want to work for them, but I still continue to help my community.* – Komu, MSM

Some peer educators stated that there was a delay of several months in paying their wages. Some reported reprimanding behaviours by NGO staff on enquiring about the reasons for the delay. After realising this exploitation, some HRGs stopped attending counselling. Some felt that there was a lack of leadership and team building in the programme operations. Hertzberg (1964) stated that these factors result in job dissatisfaction and lack of motivation to work. Additionally, many peer educators showed a rebellious attitude towards the NGO staff. A CR even cursed an NGO staff calling the staff's actions "*bad karma*", cursing him of an afterlife full of sufferings.

The reason for exploitation of peer educators could be attributed to the ineffective implementation of community outreach activities and lobbying by the NGOs and programme staff. Limited understanding of funding systems, bureaucracy, lack of transparency of funds, and corrupt behaviours from the NGO staff resulted in HRGs' lack of trust and intent in the programme. However, many peer educators continued to support the programme as they recognised its importance in preventing new HIV infections with the hope that someday they might get paid.

6.3. Uncaptured Complexities of HRG Definitions

Like any other north Indian district, Una harbours a conservative society where religion opposes homosexuality, gender wields unequal power relationships, and HIV is considered a morally charged infection. The HIV counselling programme in Una delivered homogenous services not considering the HRG's diversities. It failed to include regional diversities of HIV transmission methods and characteristics of HRGs. The following section discusses the need to provide customised counselling services based on the different user groups and discusses how HRG diversities were not effectively recognised by the programme in Una.

6.3.1. IDUs Rejected Counselling as it Challenged Their Beliefs

The counselling sessions and learning material provided by counselling centres invariably refer to sexual practice. *Baba* men did not identify as promiscuous, so they did not want to attend services dedicated to “the promiscuous” (e.g., FSWs, MSM). *Baba*-IDUs did not want to be associated with people who acquired HIV through sexual practices. This could be a barrier to their joining counselling:

> *Counselling has always been the same. There is nothing new in it. I am aware that HIV spreads through sharing of needles. Why should I go to the sessions to hear the same again? I have shared the needle. That is why, I am positive. But we all know that it (HIV) spreads through here [pointing to the genitals].* – Gabu, IDU

The quote indicates that the programme in Una delivered homogenous services not considering the HRG’s diversities. The *baba*-IDUs believed that the counselling programme focused on sexual transmission. The *babas* claimed they were celibate and did not believe the programme appreciated their celibacy.

The members of the *baba* community commonly practice marijuana smoking, a practice that they associate with Lord Shiva. Certain Hindu believers depict this practice as culturally accepted (Sharma, 1996). However, as the anti-drug regulations were made stricter after 2013 (Menguzzato, 2015), the *babas* turned to uncontrolled injecting drugs without knowing much about its safety, thus exposing them to HIV infection.

Those *baba* men who were addicted to injecting drugs only focused on getting their daily fix:

> *Look at this guy. He is positive too. No use calling him. He is dreaming [after injection] and will take a few hours before he gets conscious. The only enjoyment we are involved in is the enjoyment of injections, nothing else. We do not have any other interests or needs. The only need we have is our smoke pipe [chillum] and to*

> *get a daily fix. This counselling prevents us from doing it.* – Chela, IDU

Several HIV positive *baba* men believed that HIV infection was associated with promiscuous behaviour, homosexuality, and sex work, which they viewed as unacceptable behaviour. Such conduct was contradictory to their celibate lifestyles. In addition, the *baba*-IDUs showed unwillingness to get counselled due to their distrust in the programme and its officials, including FCS. Thus, they denied their HIV positive status and rarely took precautionary measures while injecting drugs. Given their aversion to sexual activity, they felt some loathing towards HIV counselling. The FCS struggled to keep them engaged in counselling and treatment.

> *We do not see any merit in this business of counselling. We know that they [state and NGO officials] are making money due to the services they deliver to us. But we do not think it is benefitting us but instead is more troubling to us.* – Chela, IDU

From certain remarks, like the above, the *baba*-IDUs blamed the authorities for their current situation. In 2015, the FGD reported that the numbers for *baba*-IDUs had decreased 90% since 2006. Although not clearly indicated in any reports, the CRs reported that the remaining *baba*-IDUs died of AIDS.

6.3.2. Incomplete Understanding of the Uniqueness of Baba-IDUs

India, being a signatory for the United Nation's political declaration for HIV/AIDS (1994), recognised IDUs may get involved in sex work and/or male to male sex, further increasing their risks and vulnerability (UNAIDS, 2009b). Interestingly, the formal definition of an IDU from UNAIDS did not correspond to how the *baba*-IDUs of Una define themselves. Babas shared that they do not engage in sexual activities as it was objectionable in their religion. Instead, they socially distanced themselves from other HRGs and PLHIVs.

> *There is much sex happening around us. I am aware that many guys [IDUs] go to sex workers. Some [IDUs] even go to gay men and hijras [transgender people]. But it is not us. Sex is not common among baba-log. We are virgins for life.* – Gabu, IDU

Baba-IDUs identified themselves as celibates that do not engage in sexual affairs. They did not associate themselves with other HRGs. However, the programme or UNAIDS definitions lack any mention of the celibate nature of IDUs. The programme identified IDUs based on the history and frequency of injecting drug use. It defined IDUs as "those who have injected within the last three months", and "who inject less frequently than once in three months" (NACO, 2011, p. 5). The *baba*-IDUs were displeased with the programme definition of IDUs and indicated that their identity was not captured in these definitions. For instance, the following quote depicts a specific group of IDUs in Una, referred to in the thesis as the *baba* community.

> *Baba log [people from baba community] are brahmachari [celibates]. We follow our God - Shiva. We never go for the enjoyment of sex. Even if I see a naked lady, I will not get attracted to her. If I choose between a lady and a drug, I will always choose the drug.* – Chela, IDU

Baba-IDUs identified their cultural identity as celibate and religious men. The social taboo related to HIV infection functioned as a critical discouraging factor for them from attending the programme. Flood (2004) commented that many such *babas* from various parts of India practice celibacy as a way of life which was evident in the *baba*-IDUs of Una too. These IDUs detested the association with sexual indulgences, considering it as the leading cause of HIV infection.

Although several *baba*-IDU CRs were HIV positive, they argued that injecting drug use was never the main reason for the spread of HIV. They believed that it was the involvement of the "sinners" who shared their infected needle, and *babas* unknowingly used it. It was evident from these discussions that sex was a taboo subject for the *baba* group members. The following quote portrayed their aversion to such sexual behaviours:

> *I am not a Fuddu [idiot] to believe that injections spread it [HIV]. I am a celibate, never did anything wrong; then why should I suffer? I do not want any (ART) medicine; I do not want any safety. Sinners need safety. The sinners need protection [from HIV]. We do not need any protection from you [authorities]. –* Gabu, IDU

Baba-IDUs shared the above view where they referred to those involved in sexual activities as “sinners”. Thus, they too were discriminatory towards HRGs and considered AIDS a disease of “sinners”. The *babas* used this word to refer to those men who had multiple female or male sex partners. These CRs believed that Lord Shiva punished such men for their promiscuous behaviour, resulting in the disease. In these discussions, the *baba*-IDUs also portrayed the feeling of enslavement to drug addiction and their helplessness of living a life as an HIV positive.

Although the programme provided HRGs with prevention and medical support before and after their HIV tests, *baba*-IDUs believed that this programme was not for them and that the counselling was not on their priority list. They distinguished themselves from people who have sex and/or are promiscuous. However, some *baba*-IDUs were unhappy seeking support for their condition, as expressed by one of them:

> *I did not do any wrong; I never went for sex, I never wanted to inject drugs, but I am still positive. I wanted a peaceful life, but now I cannot. Sex is the cause of all pollution. There is a lot of it [hand expression of sex] going on, here and there. Everyone has sex on their mind. But this all must end, become dust. This is the fate of this world.* – Maharaj, IDU

This statement emphasises the denial by many *baba*-IDUs regarding their HIV status. This denial continued despite repeated HIV awareness communications by the NGO staff through field visits and counselling sessions. The *baba* religiously practised celibacy and promoted it among their IDU groups. *Baba* detested sexually active individuals. They blamed both FCS and other sexually active HRGs for the *baba*-IDUs’ situation. In addition, the *babas* mourned the state of being infected with HIV and blamed the unavailability of oral narcotic drugs, making them dependent on drug injections.

6.3.3. Distinct Definitions of MSM not Incorporated in Counselling

Although NACP identifies MSM as a HRG group (NACO, 2016a), many researchers have used the word to describe a behaviour rather than an identity (Thomas, 2012). It has been acknowledged that the behavioural and sexual partnerships of Indian MSM can be highly varied, which may complicate the concepts of identity (Beyrer et al., 2010; Phillip et al., 2008).

The programme often referred to men in the context of their sexual behaviours (e.g., *kothis*—men who feminise their behaviour and state that they prefer the receptive role in anal or oral sex). The characterisation of sexual practices versus identities limited developing an empowering environment to reduce risk and vulnerability (Khan and Khan, 2006).

> *If you are looking for panthis, you will find many, but they are not true kinner. The true ones are the Ma-Pet [born to a mother], while others choose to be one [Nirvan]. I am an MSM, but I have a family too, a wife and two kids. If I want to become a kinner, I must get my penis removed, but still, I will not be a true kinner. My wife will not like it too.* – Komu, MSM

The expression of homosexuality in Una is complex. *Kinner* is an umbrella term from the local Una dialect to describe those who transgress social gender norms. Although the Indian HIV programme includes transgender people under MSM, these groups and the general population use these terms interchangeably.

Some MSM preferred to not be subsumed under the broader categories, while others prefer *hijra* or *kinner* as they felt its association with a long history, culture, and tradition in India which generally got overlooked when using catch-all terms. Others preferred MSM or ‘transgender’ when relating themselves to the programme. Many

MSM self-identified as a *kothi*—the receptive male partner in anal and oral sex. Others self-identified as a *panthi*—the ‘inserting’ male partner in anal and oral sex; or a “double-decker”—who is both. Some lived full- or part-time in the gender role ‘opposite’ to their biological sex. The problematic definition of MSM also did not capture one’s sexual identity in situations where the sex was not only with a male but also with a transgender person (*hijra or kinner*).

6.3.4. New Definitions of FSWs Not Captured by the Programme

As noted in the above sub-section, sex work in Una was managed by semi-organised channels which involved hoteliers, parlours, dealers, and other FSWs. Of note, a few FSWs preferred to sell sexual services through individual arrangements such as *bhabi,* which meant “sister-in-law” in the Hindi language. Many men had sexual favours from *bhabi* in return for food, grocery, money, or even alcohol. These men were migrants from other states, worked for unskilled labour work in Una, and lived in slums. However, these *bhabi* FSWs were even more challenging to counsel by the FCS:

> *Men from slums rarely seek sexual services from FSWs. Much expensive. They instead go to “Bhabhi”. Often, they do not use condoms; they do not understand the importance of it. These men are overprotective towards the Bhabhi and do not allow us to meet her. I got a chance to meet her once and asked her to come for counselling, I shared my number, but she was not interested in counselling or testing. I was threatened and nearly got beaten when I tried to talk with her.* – Hirant, migrant worker

During a FGD, it was revealed that there was a unique kind of FSW who lived in these slum clusters. This sex worker, referred to as *bhabi,* was a member of the same slum population, usually a wife or a relative of an existing slum dweller. Some *bhabis* ran a tuck-shop owner selling food, cigarettes, and even drugs to the slum dwellers. These sex workers had individual sex service arrangements with SMM. The following statement describes the high risk of infection involved in sexual practices with *bhabi*:

> *We are stressed about her situation and repeatedly ask her to continue with the treatment. We tried to convince her to stop meeting clients, but she was not stopping. She also has many customers, and we are unable to stop her. She is even meeting young men 15, 17 ages. They drink alcohol and have sex. They will not remember about her being positive and might get infected. We tried to ask peers to discourage her but of no use. What can we do?* – Hirant, migrant worker

Many men, mostly slum dwellers, had sexual favours from *bhabi* in return for food, grocery, money or even alcohol. FGDs further revealed that during these sexual encounters, unprotected sex was a common practice, especially when the *bhabi* got drunk. The customers of these *bhabis* were either unmarried men or married men living alone. There were incidents where these men infected their wives when they travelled to their hometown. Although the characteristics of these FSWs is unique due to their practice of solicitation, this typology of FSWs was new to the classification given by NACO (1997) and Buzdugan et al. (2009). The critical inference from these discussions was that when the programme did not understand the unique features of HRGs' experiences, HRGs were less willing to seek counselling.

6.3.5. Hijras Ignored by the Programme

As discussed in Chapter 2, the Indian HIV programme recognises the role of HTG people as integral in HIV transmission, and their HIV prevalence was noted as six times higher than the national average. However, in Una, there were no HIV counselling services for HTGs. Surprisingly, though NGO staff and MSM shared that there are HTGs in Una, the district counselling staff stated that there were no HTGs at all. The HTGs that NGOs and other MSM identified were allegedly visitors from the adjoining districts. However, a CR had a distinct perspective:

> *There are kinner in Una. Yes, genuine kinner. I have met two of them. I was told to make contacts with them and to bring them in for testing. MSM have good contacts with kinner around here. We go to many ceremonial functions that they organise.* – Komu, MSM

The CRs highlighted that they had seen many, and even met some, transgender people at local festivals for supporting NGOs in outreach activities. The *kinner* gathered in large numbers at the local cult temple on *jetha* (the first Thursday of a month) and during *daja* (ceremonies by certain lower Hindu castes). Generally, most *kinner* and MSM were committed to one male partner and rarely engaged in sex with strangers; however, some MSM did get involved in sex work.

As a close-knit community, *hijras* and MSM brought their peers for counselling sessions. However, in some instances, fear of discrimination discouraged them from visiting HIV counselling centres. Discussions revealed that the FCS had a stereotypical understanding of the *kinners.* Frontline workers identified and differentiated the *kinners* based on their physical differences, as explained below.

> *One might find a feminine figure on streets, traffic signals and public places with a hoarse voice and intimidating approach and a unique loud clap that she makes to attract attention. This person is a hijra or kinner, and this demeaning word is used to refer to the transgender, gay or cross-dresser.* – Natu, FCS

The FCS indicated that most *kinners* were open about their sexual orientation and expressed their homosexuality with what they referred to as “gay gestures”. The FCS stated that MSM who associated with *kinner* were highly expressive, which they felt intimidating. They believed that it could be because the *hijra* used a loud clap to catch attention, had a hoarse voice with a feminine attire and a blatant attitude, which they found intimidating and sometimes annoying. MSM who had not adopted transgenderism were identified in the same manner. Some even clapped loudly and wore distinctive female clothing to look like a *kinner*.

The above discussions reveal the presence of transgender people in the Una district; yet, due to the non-inclusion of transgender people in the existing HRG classification used by the district HIV programme, a transgender person could only receive subsidised services under the programme if they get registered as a MSM.

6.4. Informal Institutions Affecting HRGs' Decision to Get Counselled

Some members of the Una society considered HIV a social taboo. They stigmatised, discriminated against, and socially abandoned HRGs. However, several informal institutions played a critical role across all HRG groups in preserving their identities, supporting their interests to be hidden, and sometimes unknowingly preventing them from participating in HIV prevention activities. These informal institutions were as distinct as the religion for *baba* IDUs; for MSM, they were special groups like *dera* or *gharana,* while for FSWs, semi-organised sex work channels.

Una has an immense plurality of followers of conservative ideologies, reflecting wider Indian society. This included efforts to preserve traditional social institutions like religion. As further described below, for *baba*-IDUs living with HIV/AIDS, the devotion to Lord Shiva functioned as a psychological crutch. *Baba*-IDUs' religious beliefs allowed them to accept their conditions as their destiny. They attributed their addiction to their religious devotion; therefore, many did not seek remedy for it. Several IDUs connected with the NGOs when they were out of syringes to inject drugs and for OST when injecting drugs were not available. The peer educators, who were members of IDU groups, kept them connected with the programme supplying syringes, OST, testing, and treatment.

Similarly, some MSM preferred informal support systems and had alternatives to the counselling programme like a *dera* or *gharana.* These were sources for mental health support, and information about HIV prevention. Likewise, some FSWs preferred a private lifestyle and kept within their client and dealer contacts such as local hoteliers or beauty salons. These informal institutions are described below.

6.4.1. Baba-IDUs Found Refuge in Their Religion

Baba are nomadic celibate men with an appearance of dreadlocked hair and saffron clothes. They have consecrated their lives to the devotion of Lord Shiva and often beg for alms on the streets (Bhutia, 2018). The *baba*-IDUs used their devotion as a coping method when others did not provide solace (Charles and Britto, 2001). Studies have shown that followers of the Hindu religion associate their life with the deeds from their past life (*karma*) and trust religion for their solace (Bhangaokar and Kapadia, 2009). Denoting the historical existence of outcasts or untouchables in India, Nalini (2012) reported that such religious beliefs had fuelled discriminatory behaviours towards high-risk communities.

Among various reasons shared by *baba*-IDUs for supplying drugs to their peers, sharing needles, and not visiting HIV counselling and prevention services, *karma* was important. The concept of *karma* defines that what was done to the body can affect future existences and the health of future descendants (Hutchinson and Sharp, 2008). It propagates the philosophy of a predetermined destiny controlled by a supernatural power, which became a refuge for IDUs for not preferring counselling. The followers of Hinduism believe in propagating the concept of karma, which by definition means 'deeds'. The concept further expands to the idea of the transmigration of the soul in the circle of life and death. For those who believe in this concept, their deeds become their destiny (Bhangaokar and Kapadia, 2009). According to a CR:

> *I believe this is my karma. Lord says, never share grief with anyone. Share the happiness. I help those in grief. I make them happy [by giving them drugs]. What is more significant than happiness.* – Maharaj, IDU

The *baba*-IDUs explained that their *karma* was to supply drugs to other IDUs, and this is how they would fulfil their spiritual journey. These discussions revealed that religion played a vital role in positioning IDUs in the HIV service delivery system and would be integral in developing future prevention strategies for the IDUs of Una. The

IDUs also reported that the HIV counselling services were not available at their convenience. They were unable to access services due to its unavailability in evening hours and not being exclusively available for IDUs. Some IDUs were unwilling to attend counselling due to the fear of recrimination (UNAIDS, 2009b), which made them perpetuators in the religion's eyes for their condition, making them wrongdoers.

Baba-IDUs presented a philosophical view towards life, expressing that Shiva was there to protect and save them, stating that the time of their death was predestined and could not be altered by any measures. Some had a religion-based, fatalistic view of life. For these reasons, some refused counselling, testing, and treatment. Further analysis of narratives revealed that *baba*-IDUs showed suicidal ideation and a lack of trust in the programme. They expressed their belief that Lord Shiva would protect them from advancing to AIDS, and thus they did not need any treatment.

> *The pot of sins has been overflown, and it will burst for sure. This is what happens to the world, and it is a cycle. This all must end and become smoke. The entire world will then be reborn again. The only person who will be left is the great Lord. He is the biggest power. He is guiltless. He [Lord] made us, and he [Shiva] will sustain our lives. This is the eternal truth.* – Gabu, IDU

The above excerpt displays an outlook towards life. *Baba*-IDUs' worldviews were integrally linked with the Hindu religion and their faith in Lord Shiva. Such an outlook was also depicted in their perceptions about HIV prevention and counselling services. *Baba*-IDUs believed that the sale of drugs was a noble act and injection of drugs a path to a religious awakening, adding to the above fatalistic expression. However, this phenomenon was less prominent in other non-*baba*-IDUs, who had different interpretations of the interaction between their faiths and their high-risk conduct.

The programme lacked guidelines on managing religious factors that put IDUs at higher risk. Hinduism has a notion of a good death for its followers—a death without suffering and pain. A bad death is greatly feared and criticised as an outcome of evil deeds in this or the past life (Bach, 2017). Relating to this notion, one of the CRs stated:

> *The 'Lord' protected me in my most challenging times, and I have found my path to liberation through these drugs. Now I realise that this all was abstract. Nothing of my past or present is true. There is nothing left in my life but to meet the Lord who protected me. My life will end soon, and so will the world. And the time when everything ends, the whole universe will be born again, and I will be born too. When my time is near, I will go to heaven.* – Gabu, IDU

Several *baba*-IDUs associated drug use with the ideas of religious fanatism. These IDUs resorted to calling HIV their fate while they journeyed to spiritual liberation facilitated by the drugs. They chose these notions of religion as it gave them the reason for their sickness, which was not realised from attending the programme. Several studies indicated increasing interest in the link between spirituality and drug addiction (Joe-Laidler and Hunt, 2013; Hunt and Joe-Laidler, 2015). Spirituality had been characterised by the realisation of the holistic nature of existence, whereby addiction is associated as a method that helps achieve self-awareness. This self-awareness related to interconnectedness to a transcendent being referred to as "Lord" as referred to in the above quote. In the current settings of *baba*-IDUs, these drugs have become associated with a spiritual awakening of self-awareness and liberation, as continued by the CR:

> *These drugs are the pathways to meet him [Lord]. He can only liberate me; he can only give me solace. I have accepted the fact that I came alone in this world and will die alone too. My addiction is the only support to my solitude. This drug will show me the road to moksha [spiritual liberation]. All happens on his [Lord] wish. He must have planned a better afterlife for me.* – Gabu, IDU

It can be surmised from the above quote that spirituality and religious involvement can act as a maintaining factor to continue substance use and that the quest for spirituality can add to more ingestion of drugs. Perhaps these studies regarding drug use and liberation by Joe-Laidler and Hunt (2013) in youth cultures of San Francisco and Hong Kong can be distinguished from the experiences of *baba*-IDUs. Although both relate to drug use and its association with liberation, the *babas* experienced it in the form of a religious-based liberation, while the youth cultures were an impact of youth cultures. Though helpless of being stuck in the addiction-relapse cycle, the IDUs used this fatalistic notion of spirituality as a refuge to their current solace.

6.4.2. MSM Sought Support from Likeminded Communities

This section discusses the unique preferences of MSM for non-formal support systems. Instead of seeking counselling, some MSM preferred informal networks to the programme. CRs from MSM groups revealed their experiences of gender transitioning, social exclusion, poverty, limited access to knowledge, and mental health issues. They added that these experiences forced them to approach non-formal support systems like a *dera* or *gharana* as a source for mental health support and HIV prevention and care advice. These were semi-structured, close-knit communities led by an elderly transgender person (Nanda, 1990), whom the MSM found more understanding and trustworthy than a counsellor. At *deras*, learning from each other was noted as a customary practice. Most MSM joined the community for several reasons including their desire to express their feminine identity in an accepting environment, poverty, ill-treatment by parents and peers, after a period of homosexual sex work, or for a combination of the above.

> *He was troubled by his family because they were not accepting his behaviour. He worked with the dance club for some time to make his ends meet. Later he moved with the kinner people and started living with a mahant [at a dera]. He served them for quite some time, saved some money, and got some money from them. Then finally, He got his penis taken out surgically.* – Komu, MSM

The following explains how Una defined MSMs and, more specifically, *kinners*. During FGDs, the CRs used *kinner* to refer to MSM, bisexuals, transsexuals, transgender people, and heterosexual cross-dressing men. *Hijra* or *kinner* is an umbrella term used in India that includes pre-, post- and non-operative transsexual people, male and female ‘cross-dressers’, and people with gender-atypical appearance (UNDP, 2010). In Indian culture, a blessing from a *kinner is* considered auspicious for the potency of newlyweds or newborn babies. The *kinners* charge heavy amounts to give blessings, thus benefitting from this superstition. Sometimes, people who do not pay might end up hearing curse words condemning the newlyweds or newborn son of impotence.

FGDs revealed that several MSM lived with their families and led a double life with their wives and children to maintain their social identity. A few adopted transgenderisms due to the perceived inclusive nature of *dera* or peer pressure, which they followed to be included. Many *kinners* who become a part of *deras* agreed to specific criteria: *dai nirvana* or removal of male external genitalia. As it involved risks of infection or death, most underwent these surgeries at private medical facilities. After the MSM fulfilled the criteria laid down by the *dera*, the couple *kinners* took vows to lead a life together and support each other in sickness and difficulties. In the absence of family support, these communal houses provide cohesiveness and solidarity for their members and are often the only support system available to *hijra* individuals. The programme lacks understanding of these communal houses which the CRs suggested can act as avenues to provide targeted counselling services when collaborated with.

6.4.3. Semi Organised Sex Work Channels Impact FSWs’ Counselling Decisions

In Una, sex work is socially unacceptable. The AI experiences did not reveal any reference to brothels in or around Una; not because they do not exist, but it is a social taboo. The FSWs and their clients met privately through dealers, local hoteliers, or beauty salons which acted as their agencies for networking with customers.

Nevertheless, these channels prevented the sex workers from accessing HIV counselling. As a CR commented:

> *Some girls go to these hotels, and they work for the clients living in those hotels. The hotel managers have their phone numbers. When the clients need them, the managers make them available. We cannot have their phone numbers; managers do not share them with us. These girls rarely come in contact with us then how will we get them counselled.* – Kalyan, FCS

Ideally, counsellors should access the details of sex workers to offer them information on HIV counselling and prevention; but in Una, the counsellors did not have updated information on the sex workers. Many CRs conveyed that due to the chances of revealing their identities to the public, many FSWs preferred to conduct sex work through organised channels. These hotel staff only shared information about the FSWs to existing customers or potential customers, but not with NGOs and counsellors. Studies have referred to such channels as “protectors” of the sex workers as they play an essential role in the business of the clandestine sex trade in exchange for a fee (Harcout and Donovan, 2005).

CRs identified a beauty parlour owner who employed young girls and used the parlour to network them with the customers seeking sexual services. However, she also acted as a protector to the girls seeking her support:

> *Leela knows more about their issues. She runs a beauty parlour on an unlawfully occupied land. It has many girls from Lalsingi and other neighbouring towns who sell sex, even young ones. She has contacts and knows how to find ‘such’ girls and potential buyers. She does not care about prevention activities; she says she knows more and can instruct her girls better. Even [Leela] asked for money [from counsellor] to get counselled. It is not easy to counsel her. She does not trust us and hesitates to disclose any information, does not allow us to contact the girls. These girls seldom come to us and give the wrong contact, wrong name. We are not allowed to ask for their IDs. If tested positive, they stop attending phone calls or counselling and even do not get treated.*
> – Kalyan, FCS

The FSWs were extremely careful in protecting their identities because disclosure may dishonour their family and damage their own social status. As described above, some FSWs used beauty parlours for solicitation. These FSWs often change their phone numbers to avoid getting tracked by the police. However, this makes it difficult for the FCS to contact them. These networks also inhibit FSWs from seeking counselling support. A FSW CR's view was that although sex work could be a lucrative business, sex workers rarely reap the benefits of their revenue through organised channels. However, they also agreed that such semi-organised channels were less risky to independent sex work. Overall, these semi-organised networks impacted the counselling decisions of FSWs.

6.5. Other Social Factors Impacting Access to Counselling

The following are two unique factors that affected access to counselling. The first refers to the unavailability of IDUs for counselling due to their travelling and drug peddling behaviour. The second factor refers to unreported transgender people being excluded by the services under the programme unless they get registered as a MSM.

6.5.1. Travelling and Drug Peddling a Barrier for IDUs to Access Counselling

The HIV control programme in Una provided counselling and testing for HRGs for free. However, *baba*-IDUs did not go for their regular testing because of travelling or peddling drugs. The following quote describes their practice of selling drugs to their fellow IDUs:

> *I joined 'babas,' and now I wander with them. We do not stay in one place. We are wanderers. We live under this tree [at a local park], beg for alms, and pray to Lord. I help others like me, showing them the path. Many pay me for drugs [both injecting and other drugs]. Some do not inject but only smoke [marijuana] and drink [alcohol]. Nevertheless, they may join us someday, and when they do, I will provide them with injecting drugs.* – Chela, IDU

The CRs shared information about the drugs they used and peddled. *Baba*-IDU brought *addnok* (an injectable opioid drug named buprenorphine used to treat opioid use disorder as a sublingual dose) (Rao, Agrawal and Ambedkar, 2014; Shulman, Wai and Nunes, 2019) and other drugs to their fellow IDUs and acquaintances. The peddling of drugs encouraged *baba*-IDUs to play a significant role in distributing injecting drugs to the local IDUs of Una and enabled them to become local drug vendors for Una.

When *baba*-IDUs travelled to nearby cities to buy drugs for their use and sale, they missed their counselling sessions on the travelling or peddling day. With the ban on the over-the-counter sale of *addnok* from local pharmacies of Una, the only way to stop these IDUs from doing injections (or selling) was to discourage them from travelling. However, the lack of identity cards enabled them to travel to nearby cities without being identified. If detained, it also favoured their early release as the police found getting them imprisoned a cumbersome procedure.

6.3. Summary

This chapter examined perspectives aiming towards creating an inclusive and safe programme that safeguards the rights of HRG communities and facilitates accessible and effective services for them. The CRs shared ideas on how counselling was understood and how it has failed to improve the lives of HRGs. Analysis included the generated visions and an explanation of how counselling is understood to engage in collective ideas of future HIV counselling programme for Una.

CHAPTER 7 – DISCOVERY, DREAM, DESIGN, AND DESTINY

EXTRAPOLATING IDEAS FROM 4D STAGES OF APPRECIATIVE INQUIRY

> *If we cannot make landfall, then our ship must have been constructed on the high seas—not by us but by our ancestors. Our ancestors must have been able to swim and carpentered a raft out of driftwood. They then continually improved on this raft until it became a comfortable ship. So comfortable that we no longer dare to jump into the water and start from scratch. To solve the problem, we must put ourselves in such a shipless condition, that is, bereft of language, and then attempt to retrace the activities whereby we could, while swimming free in the middle of the sea of life, build for ourselves a raft or even a ship.*
>
> Lorenzen (1987)

7.1. Introduction

The previous two chapters focused on the thematic analysis of findings from FGDs, reflecting on the HIV counselling-related experiences from the perspectives of CRs and how they critiqued the HIV counselling programme delivered in Una. The chapters presented the challenges to programme effectiveness from the CRs' lens and created the foundation for the following discussion. The challenges were categorised into management and organisational (Chapter 5) and social factors (Chapter 6). When analysing these factors and positioning them against CRs' discoveries, dreams, designs, and destiny, it was observed that few positive experiences or proposals emerged for making change. This is because the positive themes flow throughout and are not exclusive to specific sections, as previously mentioned. The analysis of the narratives provides a foundation for constructive criticism and design for change. In this chapter, I, as a participatory researcher, reflect on the potential for design that emerges from the previous chapters using the 4Ds structure to shape my arguments: Discovery – examining the past strengths of the programme; Dream – examining CRs' visions for an effective HIV counselling programme; Design – examining how CRs would design it for the Una district; and Destiny – analysing the future of the design.

Broadly, the discoveries, dreams, and designs relate to mitigating the challenges raised in programme designing, implementation, and organisational practices. They focus on enabling more HRGs to get counselled and tested, thereby reducing their vulnerability to HIV infection.

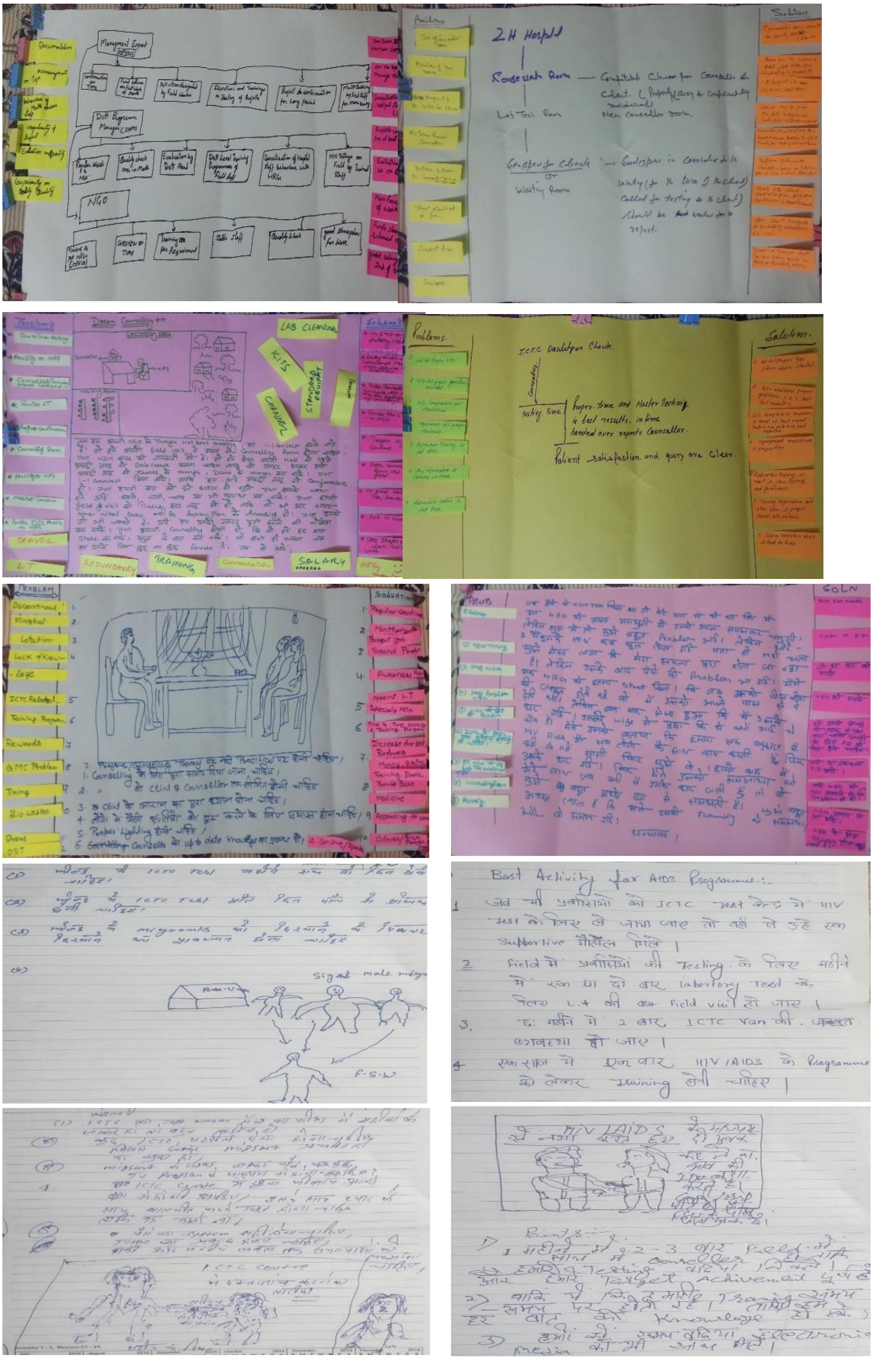
7.2. Discovery, Dream, Design, and Destiny for HIV Counselling Programme

Of note, several CRs' responses did not consistently focus on the positive. At times, it was challenging to extrapolate positive perspectives from CRs as they were rooted in the problems of the programme. Even after constant prompts and gentle reminders to encourage positive responses, CRs tended only to share their critiques of the programme and had little to say about their dreams and designing the programme.

Once CRs had shared their criticisms about the programme and emphasised how ineffective it was, they embraced the positive orientation of the AI exercise and gave positive inputs. When requested to share what they felt was best in the programme, they had a few insights that became the foundation for the probing questions of the dream phase. After CRs had described how they imagined the future programme, they drew the plan to achieve these dreams (see Figure 7.1).

Figure 7.1

Design Drawings by FCS During AI



Many CRs chose to draw dream images on coloured flipcharts with marker pens, while others preferred to draw them on a page from the back of their notebooks. Some CRs listed the problems on the left side of the chart and the solutions on the right, and used the middle area to picture their idea. Others chose different presentation styles. Some CRs imagined a perfectly operating counselling session, while others presented community-based experiences in their images. Some focused on the positive, others on the programme’s existing (negative) features. These ideas have been used in different sections as CRs’ dreams and design suggestions.

The strength-based ideas that emerged during these exercises specifically aimed to develop an effective counselling programme. A remarkably comprehensive depiction expressed a counselling programme that adhered to programme guidelines had a client-centred counselling strategy, strategies around individualised counselling and developing linkages for HRGs, improved data sharing and reporting capabilities, techniques on motivating staff and delivering wages on time, and zero tolerance to discrimination to create a society that supports HRGs. Each idea has been expanded into four stages: best practices *discovered* by CRs, their positive *dreams* of the future programme, their *design* for an improved programme and how the *destiny* of the programme design would look.

The CRs discovered the existing strengths and dreamed of a programme without organisational and management barriers. They envisioned programmes that gave more power to HRGs designed based on their requirements. The Design for an effective programme focused on abiding by the revised programme guidelines. It also aimed to improve client privacy and staff accountability. The Design aimed to digitise client records, making structural changes to the counselling and testing rooms to make sessions more private. CRs aimed to design a more supportive programme that gives options to HRGs for employment and social living. The Destiny (or Delivery) was the ultimate step of AI’s 4Ds, where the design feasibility is critiqued.

It has to be acknowledged that many of the points in the Destiny (Delivery) section were not narrated by CRs. They have been extrapolated from the findings from the first three stages. This section articulates how CRs’ design would turn out in the actual settings of Una. As the current the HIV counselling programme in Una is not available, real scenarios have been conceived based on scholarly publications. The design implementation in the actual setting has been discussed in parallel with prevalent organisational and socio-political factors that may impact the programme. There were several challenges to implementing the subpoints outlined above in real Indian settings for HIV programmes (Misra et al., 2016). Some potential reasons why these subpoints may be challenging to implement as a Destiny (Delivery), have been discussed in the following sections after the ideas from Discovery, Dream, and Design.

7.3. Developing a Counselling Programme Adherent to Updated Guidelines

Chapter 5, section 5.3, emphasised that counselling sessions conducted under the HIV counselling programme delivered in district Una did not conform to the programme guidelines. Participants called for compliance with the guidelines regarding the duration of counselling sessions (actual sessions were shorter), and the guideline recommendations for gender-matching. The guidelines called for well-resourced programmes. However, the programme was under-resourced. Hence, the key areas of concern were the less duration of counselling sessions, lack of workforce to support the counselling burden, and the absence of gender-matched counsellors.

7.3.1. Discovering Best Practices Where the Programme Adhered to Guidelines

In response, CRs reflected upon the best experiences from the past. For example, they shared that longer counselling sessions had better results with medication adherence when the counsellor spent more time with the client and adhered to targeted counselling guidelines. FCS stated that the guideline recommended additional staff be provided in case of higher workloads. A female counsellor can also be requested by the client in case they need gender-matched counselling. They shared that FSWs preferred to talk with the female counsellor and felt comfortable discussing these physical issues with them. Another strength they shared was that they wished for the services provided to remain free to HRGs as it encourages them to join.

7.3.2 Dreaming a Programme That Adhered to Counselling Guidelines

CRs wanted the guidelines for district-level programme operations to be routinely updated based on the HRG’s changing requirements. They requested that staff could be trained periodically about these changes. AI revealed that both FCS and HRGs dreamed of a counselling programme where the number of HRG clients was higher, and non-HRG clients were less. They suggested that if only HRG clients were referred to FCS contracted under the programme, their numbers would be much more manageable for FCS. That way, the FCS can give more time to HRG clients for both pre- and post-test counselling. The CRs also dreamed of a programme that recognised the importance of counselling. This programme would provide more extensive, effective counselling sessions, regardless of whether the test results were positive or negative.

The following quote by an IDU indicates that when a counsellor spends enough time with the clients and adheres to counselling guidelines for IDUs, the IDU client also adheres to safe injecting practices.

> *At that time, no one told them that the syringes should not be shared. They used to make one mixture, and all of them used to*

> *share that needle, poking them in all of their veins. They tell us that the injection is the only way these people can get HIV as it transfers through the blood. I had made this compulsory that I am not using anyone else's syringe or needle. It is a mistake and your own serious mistake. Otherwise, the chances of infection are high. I do get myself tested for HIV regularly, and it is negative all the time. I never make any mistake as I judiciously adhere to the rules of safe injections.* – Avin, IDU

7.3.3. Designing a Programme That Adhered to Updated Counselling Guidelines

In Chapter 5, 5.2., FCS criticised the programme for not adhering to national guidelines. They suggested that the counselling session was too short, and the staff were few. In Design, they stated that the counselling and testing resources allocated for HRGs should only be utilised for eligible HRG clients. The authorities should discourage NGO staff from bringing in random people to increase the counselling numbers.

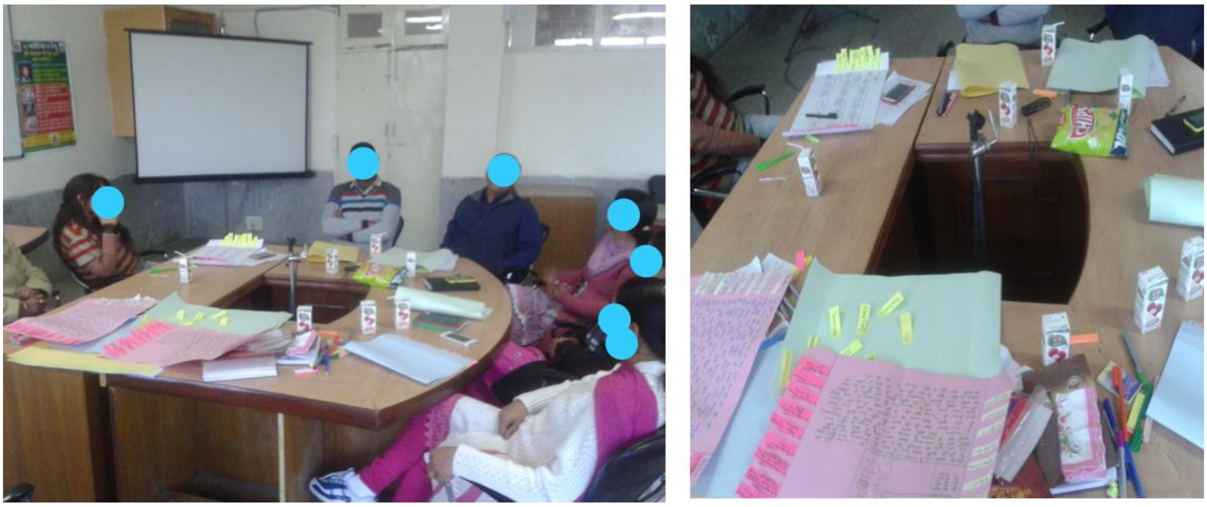
CRs suggested that female FCS be employed to provide gender-matched counselling sessions that accept the social construction of Indian society, where some women or transgender clients face are hesitant to talk about sexual health with a male counsellor. FCS also recommended a programme that encouraged HRG clients to seek services and spent fewer resources on non-HRG clients. They suggested that non-HRGs can be provided with separate counselling provisions. Such practices would allow HRGs to receive a more collegial counselling session with acknowledgement of their distinctive needs.

The CRs communicated that counselling sessions should conform to the international guidelines for a standard HIV counselling session. Figure 7.2 was taken during the Design stage of AI showing FCS interacting. Each session should take at least 40 minutes, including time for pre- and post-counselling sessions and excluding time for taking the HIV test itself. Tests should always precede a counselling session as it keeps the clients adhering to regular testing. The CRs further visualised that HIV counselling should not be just a tool to prepare clients for HIV test results and share results. Neither should it be just a tool for treatment referral and to measure treatment adherence. The programme should emphasise counselling as a method of HIV prevention and rehabilitation of clients.

The staff should also communicate negative test results to the clients and encourage clients to come back to attend post-test counselling, regardless of the test results. FCS further suggested that the programme should encourage FCS to ensure the delivery of comprehensive post-test counselling, not solely for reporting purposes. These processes will lead to greater workload, so authorities should recruit more counsellors to accommodate the higher number of clients needing longer counselling sessions while complying with the counselling guidelines of 40 minute sessions.

Figure 7.2

Interacting with FCS During the Design Stage of AI



7.3.4. Delivering an Effectively Managed Organisational Programme Design for HRGs (Destiny)

Several design suggestions have been described in Chapter 6, and their Delivery has discussed in the following sections. However, certain management and organisational limitations portrayed in the results and reported by several research studies could inhibit their execution (Misra et al., 2016).

There are legal and regulatory barriers (Chakrapani et al., 2009) that prevent the implementation such as restrictions on the provision of harm reduction services including OST and prophylactic treatment. Moreover, staff or clients have observed resistance to change (Patel et al., 2018), which can make it challenging to implement new initiatives or approaches.

Other barriers might be related to difficulties collaborating with organisations (Chakrapani et al., 2009). Coordinating and collaborating with other organisations and stakeholders, such as community-based organisations like *dera*, and local health departments (Chinnappan, 2021) may require time and resources. Overcoming resistance may take education, training, and efforts to address concerns or objections (Patel et al., 2018).

HIV counselling programme faces challenges in securing sufficient funding to support the implementation of the points outlined above (Liambila et al., 2018), making it a challenge to invest in additional staff or resources or to provide targeted support and resources for HRGs. Moreover, ensuring the sustainability of these resources may also be challenging (Liambila et al., 2018). Additionally, collecting and analysing data on the effectiveness of these design suggestions may be difficult, as it may require the development and implementation of appropriate monitoring and evaluation systems (Gupta et al., 2018).

Digitisation is part of the updated programme guideline and has been proven as an essential step in improving the effectiveness of any PHP. Digitisation means conversion of information from a physical or analogue format (e.g., paper documents or audio recordings) into a digital format. Digitisation has improved access to care for HIV patients by enabling remote monitoring and consultations through telemedicine. This can be especially beneficial for patients living in rural or underserved areas, who may have limited access to healthcare facilities (Smith and Badowski, 2021). Digital tools, such as smartphone apps or wearable devices, help to improve treatment adherence by reminding patients to take their medications and providing support and education about their treatment regimen (Duthely and Sanchez-Covarrubiaset, 2020). It further improves the accuracy and timeliness of prevention and care (Jain and Sharma, 2016). Digitisation has helped to reduce costs and improve the efficiency of care for high-risk HIV patients by streamlining processes and enabling the sharing of resources (Adam and Fazekas, 2018).

Digitising helps to reduce the risk of corruption, as it becomes more difficult for staff members to manipulate or mismanage financial resources (Adam and Fazekas, 2018; McConnell et al., 2022). By digitising financial transactions, it becomes easier to track and record the flow of funds within the HIV counselling programme in India. Techniques like time stamps and location tracking help increase transparency of financial transactions (Sundararajan et al., 2022) which makes it easier to hold staff members accountable for their actions and ensure that funds are being used appropriately in the HIV counselling programme. This can improve the programme’s overall effectiveness and integrity (Jain and Sharma, 2016).

There are several challenges to implementing digitisation and other transparency measures in the context of Una which are similar to several other Indian districts. Access to computers and the internet is still limited, especially in rural or disadvantaged areas (World Bank, 2019) making implementing digital systems for tracking financial transactions or storing patient data difficult. For digital systems to work effectively, there needs to be a reliable infrastructure in place, including access to electricity and stable internet connections (Internet and Mobile Association of India [IAMAI], 2019). These infrastructure requirements may not be met in Una.

7.4. Devising a Private and Accessible Counselling Programme

Privacy and confidentiality have been raised as significant challenges faced by CRs (Chapter 5, section 5.2). Lack of privacy and confidentiality for HRG clients attending the HIV counselling programme was of utmost importance for CRs. FGDs revealed that, as there is only one district hospital, the hospital staff knew the local population well, especially the HRG clients who commonly visit the hospital for other treatment reasons, such as STD clinics and pre-natal clinics. Often the people in waiting areas could identify HRGs when the hospital staff called their names or place of residence while waiting to get counselled. On reflecting upon organisational challenges—lack of privacy and unrestricted access to counselling and testing rooms by outsiders—HRGs suggested making timings separate from regular hospital hours. After-hour and community-based counselling would be convenient and more private for HRG clients.

7.4.1. Discovering Best Practices for a Private and Accessible Programme

This section discusses the ideas and best practices that CRs shared from their past to address the challenge of lack of privacy and ease of access in HIV counselling and testing centres. The CRs were asked to think of best practices that have been successful in the past or ideas from other services that may help in eliminating lack of privacy and ease of access. One of the FCS pointed out that the TB centre at the hospital was the best example. A HIV counselling and testing centre should be built outside the main hospital, as was done in the case of the TB centre. They acknowledged that keeping the TB clinic separate from other departments was primarily due to the high contractability of the infection through cough and sputum. However, its location was private and restricted.

Also, FCS favourably mentioned the accessibility of counselling facilities located within the NGO premises rather than at the hospital. Additional best practice was the NGOs' focus on privacy and support of peer educators for comfort during counselling. FCS also suggested that the mobile testing vans and community-based testing that used to be undertaken before 2010 were a good service and should be replicated.

Overall, CRs identified several successful strategies from the past and other best practices for improving privacy and accessibility in HIV counselling and testing, including separating the clinic from the main hospital, locating counselling facilities within NGO premises, and utilising peer educators and mobile testing vans. These suggestions highlight the importance of considering both privacy and convenience in their Dreams, Design, and Delivery of the programme.

7.4.2. Dreaming for a Private and Accessible Programme

The FCS and HRGs desired a separate venue for delivering counselling and testing services to protect the client's identity. The CRs imagined a counselling centre that could deliver private counselling sessions in comfortable settings. They dreamed of a supportive environment for their clients when visiting the counselling centre, which can be designed with them being called at separate times. They desired a programme dedicated to accessibility for HRGs at convenient times and locations. The HRGs imagined that the counselling centres, testing labs, and NGOs served clients in the evening and late hours. They need swift attention, especially in winter.

The following section involves the separation of counselling appointments for the general public and HRGs, as well as the role of FCS in facilitating counselling and increasing attendance among HRG clients. The CRs believe that a deeper understanding of how HRGs define themselves will improve counselling and lead to more HRG clients at the centre. This is based on the idea that FCS can closely observe the lives of HRGs and understand their priorities and healthcare needs which may, in turn, facilitate counselling and increase attendance.

HRGs visualised that FCS could see their lives closely, so they understand the priorities and healthcare needs of HRGs. This might both facilitate counselling and increase attendance by other HRG clients. CRs believed that a better understanding of how HRGs defined themselves would improve counselling and help recruit more clients to the centre. The following quote was shared by a FCS indicating that the counselling rooms at some NGOs were more equipped.

> *We have better arraignments at our NGOs than the arrangements at the hospitals. We have a good room for the counsellor, a chair table, and a closed arraignment for the counsellor. When the counsellor is busy with the client, no one disturbs them, and other staff go out from the other side.* – Hira, FCS

The separation of counselling appointments for the general public and HRGs is necessary for privacy reasons. Furthermore, HRGs want FCS to come to them (or to their NGOs) so counsellors understand more intimately what HRGs' lives are like. This approach may improve the overall effectiveness of counselling and attract more clients from HRGs. The involvement of FCS in counselling may be beneficial as they can better understand the lives and needs of HRG clients, potentially leading to improved counselling and increased attendance at the centre.

7.4.3. Designing a Private and Accessible Programme

To promote privacy in counselling programmes, FCS suggested that the counselling rooms be situated away from the main hospital building and soundproof. The programme should obey guidelines for audio-visual privacy, where patient safety and confidentiality are of primary importance. Based on the narratives from the drawings, CRs designed the counselling rooms with one-way opaque glass, enabling

FCS to see people waiting outside but not allowing outsiders to see inside the counselling room. Their counselling and testing centre design had a separate entry and exit. The corridors were closed, and no outsider was allowed to enter when counselling or testing was conducted. They insisted that external staff members should be asked to make prior appointments before visiting the testing lab or counselling room. One crucial suggestion discovered from other practices was having a building similar to the TB centre at the hospital that was positioned outside the main building.

Some FCS had recommendations beyond privacy factors that led to the following design suggestions. A few discussed counselling room size, appropriate ventilation, and other miscellaneous requirements for making the counselling and testing process more effective. CRs designed counselling and testing centres in well-lit and ventilated rooms, with drinking water, rubbish bins and clean toilets for the clients. The centre should also have a whiteboard and secure cabinets to store consent forms, other paperwork, and a few extra chairs for a group counselling session. FCS requested that every centre have a computer with a UPS, internet access, and a printer to store and report client information. They also added that despite the regular purchase of computers and internet dongles, the devices did not operate due to inadequate network signals and maintenance. For example, the computers at the office and the conference hall were damaged due to lack of maintenance.

The CRs designed a private, separate waiting area for the HRG clients and suggested multilingual signboards/maps at the gate and around the hospital premises make the centre more accessible. These signboards would allow clients to reach the counselling centre without asking others, thus protecting their privacy.

HRGs suggested that NGO offices and counselling centres be available at convenient times and venues closer to HRG communities for accessibility. They imagined counselling rooms available at NGOs open for the entire day, along with testing provisions in the field and for longer hours. Counselling services should be made available at the times and places when HRGs are available, like in the evenings and closer to their communities, to accommodate the erratic and unstable nature of the high-risk jobs that most HRGs do. The counselling and testing centre should allocate designated hours to serve HRGs and not mix their timings with the general population. The counselling and testing services should be available during the same business hours in winter and summer. The programme should install mobile testing vans and conduct community-based testing for remote areas. Due to limited staff to entertain this Design, FCS suggested adding more workforce for long hours and when there are long queues for testing/counselling.

With these provisions, clients can avoid crossing the crowded hospital areas to the counselling room. No outsiders, friends, or other staff members should be allowed to enter the counselling room or testing lab before, during, or after the counselling and testing procedures. This is to avoid identifying clients who come for counselling unless requested by the client as a support person. Furthermore, privacy would be protected by providing limited access to counselling and testing records by the hospital staff, senior programme staff, and clinicians. They also recommended that mobile centres be made available for outreach activities visiting hotspots where HRGs congregate. HRGs pictured FCS were having special days when they accompanied the clients to their homes and communities to live there for a day or two, thereby better understanding HRGs' lives, priorities, and healthcare needs.

7.4.4. Delivering a Private and Confidential Counselling Programme for HRGs (Destiny)

For delivering suggested designs to make HIV counselling programmes effective in current contexts, it is imperative to implement measures to ensure the confidentiality of high-risk clients, reduce stigma and discrimination, and improve access. Some of the steps that can be taken have been described below.

The Una district authorities can implement strict confidentiality policies to ensure that the personal information of HRGs of Una is not disclosed to anyone outside the programme (Obermeyer et al., 2012; Sastry et al, 2004). District authorities can advocate for strong data protection laws and regulations to protect the personal information of high-risk clients (Divan, 2018). Programme officials and the NGOs associated with the programme can advocate for policy and legal changes at the district level to protect the rights and privacy of HRGs (Rao et al., 2014). However, implementing such policies is challenging due to the country’s complex legal and regulatory landscape (Obermeyer et al., 2012; Sastry et al, 2004), and challenges related to advocacy and lobbying efforts (Sahu, 2016; Rao et al., 2014).

The programme can offer anonymous testing and counselling services, allowing clients to receive counselling without disclosing their personal information (Obermeyer et al., 2012; Sastry et al, 2004). However, it is difficult in Indian districts like Una due to logistical challenges and the need to ensure the quality and accuracy of the services provided (Obermeyer et al., 2012; Sastry et al, 2004). There are challenges related to the availability of resources and trained staff to implement these services (Rao et al., 2014).

Improving client privacy and confidentiality must be an essential during budget allocation. It should be mandatory practice to maintain privacy of clients. Provision for punitive actions against staff who violate privacy can also help. Additionally, the programme can set up internally audited and secure ways of sharing patient information with other hospital staff.

Investing in additional staff and resources, and implementing more efficient appointment systems have been effective in reducing delays and improving the accessibility of the programme (Gogia and Sachdev, 2010). Also, offering evening and weekend appointments has improved the utilisation of HIV counselling and testing services among high-risk individuals in India (Nyamathiet al., 2011). Cultural and social factors, such as family and work commitments (Patel et al., 2018), make it difficult for HRGs to access HIV counselling services at convenient times. Offering flexible hours and evening and weekend appointments could accommodate these factors (Patel et al., 2018) and improve service utilisation (Nyamathiet al., 2011). However, similar to any Indian district, HIV counselling programmes in Una have limited financial and human resources, which makes it challenging to invest in additional staff or resources to reduce delays and improve efficiency (Gupta et al., 2018). It may also be challenging to allocate a budget for longer hours of operation and a larger workforce (Liambila et al., 2018).

Mobile HIV counselling and testing services can effectively increase service uptake among India's high-risk populations (Kumar, Singh and Singh, 2017). The provision of bus passes or subsidising the cost of transportation has also been a factor in improving the utilisation of HIV counselling and testing services among high-risk populations in India (Gogia and Sachdev, 2010). However, some HRGs of Una live in remote or difficult-to-reach areas, making it challenging to provide mobile options for them (Nittas et al., 2020). It would also be challenging to allocate a budget for providing transportation assistance (Liambila et al., 2018). Collaborating with local organisations that serve high-risk populations, such as substance abuse treatment centres and community health clinics, can also help to provide counselling close to them at a lower cost (Sharma et al., 2016).

7.5. Customising Counselling Programme for HRGs

As indicated in Chapter 6, section 6.3, the HIV counselling programme in Una was designed for HRGs. However, specific HIV counselling provisions were not always available for these HRGs. The data showed that HRGs were more vulnerable to HIV and associated complications due to social factors such as stigma, discrimination, and lack of access to healthcare. These barriers to accessing services contributed to higher rates of HIV transmission and poorer health outcomes for HRGs. The programme could not effectively identify the needs of HRGs or recognise the unique challenges faced by these groups. This lack of recognition was critical in redesigning the counselling programme to better serve HRGs and address their specific needs.

7.5.1. Discovering Best Practices for a Counselling Programme for HRGs

When asked to identify a best practice or strength from the past, CRs noted that targeted counselling protected clients from HIV if delivered effectively. For example, FSWs who were educated about their HIV risk were more likely to use condoms and practice safe sex. Clients made better health decisions when receiving comprehensive, customised counselling. Also, with the targeted counselling, PLHIVs were able to protect them from the complications of HIV. In cases where both partners were infected, using a condom and taking regular treatment helped them lead healthy lives. More SMM from local slums attended counselling when it was provided at accessible locations for slum dwellers. Finally, the clients tended to trust the NGOs more when the NGO peer educators were members of the HRG community. These discoveries suggest that targeted, culturally sensitive counselling can effectively improve HIV prevention and care among high-risk populations.

7.5.2. Dreaming for a Counselling Programme for HRGs

It is already clear that the purpose of customising services was so that HRGs get accessible, respectful, and appropriate counselling. This content describes the dreams of various HRGs concerning their unique needs and challenges related to HIV prevention and care. They wished for counselling programmes to be tailored to meet their specific needs. IDUs wished for counselling services more relevant to their specific needs as IDUs rather than being too generalist. They want specialised counselling sessions that focus on safe injection practices rather than other routes of HIV transmission that are not relevant to them. IDUs desired a programme that treats them as individuals and meets their specific needs, allowing them to access regular healthcare services and better de-addiction facilities without fear of stigma or discrimination. Additionally, IDUs hoped for more appropriate conduct from hospital staff to prevent accidental venepunctures, and they wished for experienced staff to take their blood samples.

Baba-IDUs wished for a programme that respects and accepts their religious beliefs. They want the programme to recognise that their high-risk behaviour is related to drug use rather than sexual behaviour. *Baba*-IDUs need counsellors who understand their unique needs and challenges. They desired a programme that is sensitive to their cultural and religious context and keeps their identities confidential to protect them from stigma. *Baba*-IDUs did not want to be viewed as associated with MSM. Their needs were unique. They wanted the programme to recognise them as primarily celibate and getting high was a way to achieve liberation (moksha). Hence, their high-risk behaviour was related to drug use only.

HRGs dreamed of a programme that provided MSM with an individualised counselling programme based on their high-risk behaviour and need. MSMs wanted the programme staff to understand that several of them lived dual lives where they were a part of a heterosexual society. They wanted the programme to keep their identities confidential so that they did not suffer from the impacts of stigma. They also wished the programme to understand the uniqueness of different MSM and their cultural contexts, and not group them when delivering services.

MSM dreamed of a programme that promotes their supportiveness in society. They wished no MSM joined semi-organised channels such as *deras* (social places for gay people) because they were stigmatised elsewhere. In cases where MSM stayed at *deras* by choice, the programme could work along these channels to develop a better rapport to disseminate information about safe sex and counselling programme.

In Una, as HTG, often called *hijra*, were not having a separate category under the programme, many were counted as MSM. As many MSM closely interacted with HTG people, they desired that the HTGs were recognised as residents and included in the programme rather than considered non-residents. They desired a programme that counts HTGs as members of HRGs and also provides individualised services for the HTG community.

Additionally, FCS wished for the programme to recognise *bhabi* FSWs associated with slums in Una as a unique category and to increase engagement with these FSWs to ensure they are regularly tested and treated for HIV. FCS wished that the programme identified *bhabi* FSW associated with slums in Una as a unique FSW category. Several SMM, including many minors from Una, practised unsafe sex with *bhabi* FSWs while intoxicated. FCS wished to increase the engagement of the *bhabi* FSWs with the HIV counselling programme and other healthcare services and to ensure that bhabi FSWs were tested regularly and treated.

Some FSWs worked at brothels, while others used their connections with hotels and beauty parlours to find clients. The brothel owners and intermediaries who connect FSWs with customers discouraged them from participating in HIV control programmes. It is possible that they did not want the FSWs to leave the business. The FSWs wished that the HIV control programme would support their work through these channels and maintain a relationship with the owners of these establishments. The reason being the brothel owners and intermediaries at hotels and boutiques do not prevent FSWs from joining the programme. The FCS also desired that the brothel owners and hoteliers cooperate with the programme activities.

The FSWs also wished the programme could promote alternative employment opportunities that empower sex workers to leave the industry if they choose to do so. They wanted the programme to have avenues for skill-based training and education, as well as promoting entrepreneurship and small business development that can help get such employment. A FCS commented on how she felt about employment opportunities given to FSWs.

> *Suppose the government is ready to rehabilitate these types (of FSWs) from the massage (parlour) and (sex) workers and give them some small-scale jobs in NGOs to get some money for their life. That will be great.* – Oni, FCS

Although this may be beyond the scope of HIV counselling programmes, FSWs and MSM CRs hoped for broader social, economic, and legal reforms that address issues such as violence, emotional trauma, and discrimination against HRGs. Some FSWs also hoped the programme addressed poverty, lack of education, and discrimination against HRGs. Others dreamed of having more robust policing against drug peddling so that drug users were not able to procure injectable drugs. Some FCS also wished that prostitution was legalised so that FSWs could have more support from society. MSM dreamed that the programme could make society accept their sexual orientations. They all wanted the programme to protect them against domestic violence. Although many of these suggestions are beyond the limits of the programme activities, the guidelines do mention that counselling could provide such advisory linkages for HRGs.

HRGs wished for some services that were outside the purview of the programme. The CRs also demanded the HIV counselling programme provide mental health counselling and advise better behaviour change support. They wanted a programme that was not limited to advice about HIV testing and safe sex. Some even suggested psychological consultations for HRGs who underwent trauma. Both FSWs and MSMs wanted to network with agencies, such as the police, who could protect against violence and act on discrimination-related complaints. Although not directly addressed through the programme, these suggestions point to some critical issues that HRGs face daily. CRs wanted de-addiction support and rehabilitation centres to be more supportive and adopt client-friendly methods for behaviour change.

Overall, various HRGs have unique dreams for HIV counselling programmes tailored to their specific needs and challenges. These include specialised counselling sessions, sensitivity to a cultural and religious context, support in situations of violence and emotional trauma, and recognition of the unique needs of different HRG groups. The following sections describe how these CRs planned to achieve these dreams.

7.5.3. Designing a Counselling Programme for HRGs

The CRs' dreams expanded into a suggestion for contextual counselling that addressed each HRG's requirements separately. FCS advised that the clients should be assessed for their mental health needs, suggested behaviour change measures, and wanted follow-up measures. Although some suggestions seemed out of the programme's scope, they even advocated that HRGs live in a supportive society that helped them to get safer jobs. This required training of staff or recruiting staff with skills for delivering complex services, which they suggested to be addressed at the earliest.

One example was psychological service for substance-dependent HRGs with provisions to rehabilitate IDUs into society. They recommended de-addiction support and rehabilitation centres to be more supportive and adopt client-friendly methods for behaviour change. They advised that the service should have sufficient availability of testing kits, OST, rehabilitation facilities, and accessible treatment provisions for HRG clients. The programme should have adequate mental health support through NGOs and de-addiction centres.

FSWs should also receive rehabilitation support to acquire the necessary skills to obtain regular jobs. For example, alternative employment for FSWs would prevent them from going back into forced prostitution due to poverty. The programme needs to do community-based interviews with several HRGs to better understand the current programme requirements.

FCS and IDUs suggested individualised counselling sessions for IDUs and *baba*-IDUs that upheld their religious and cultural sentiments. These sessions should include techniques to stop injecting drugs, alternatives to injecting drugs, and doing injections safely. IDUs suggested that awareness campaigns highlight the difference between various HRG groups and how they contract HIV. These campaigns should help IDUs practice safe injections or adopt safer modes of addiction. Although outside the programme’s scope, some design suggestions include banning illegal drugs altogether and enforcing punitive actions against drug peddlers. Another suggestion was the legalisation of non-injectable drugs so that there could be some control over their sales and consumption.

The CRs suggested that the counselling and testing team conduct more community activities to encourage clients to engage in regular counselling and testing. They need to visit the community at least twice a month to counsel and test those clients who cannot visit them. The CRs added that the van from the counselling centre should be made available for these visits, and the testing team should not limit their number of tests to five on those days. The counselling team should use educational movies to encourage HRGs to engage in HIV prevention activities.

For *bhabi* FSW, a similar community-based approach was suggested where the linkages from slums could be used to get them tested and treated. However, FCS going to slums need specific training and skills to understand the dynamics of a slum. They need to build rapport with the SMM who restrict interaction with *bhabi* FSW. Another design suggestion was conducting awareness activities in slums to discourage unsafe sex and sex while intoxicated. The FCS further added that all FSWs should be required to register with the programme with stringent actions against those who do not comply.

A significant point emphasised in FGDs was the role of informal support groups in supporting HRGs. MSM had good contacts with HTGs, and their networks can be used for HTGs recruitment. Ideally, the programmes should attempt to channel the capacities of informal institutions that support HRGs, develop a better rapport with the clients, and disseminate knowledge of best practices for HIV prevention. Another way of rapport building was providing legal support to the clients who ended up in police custody due to their high-risk behaviours.

CRs suggested a programme that ensured HRGs were counselled and provided with safe sex advice, condoms, and regular tests wherever necessary. HIV and STD treatment should be mandatory for every infected HRG attending the programme. Prophylactic treatment should be made available for HRGs without delays wherever necessary. Some HRGs detailed how programmes could provide specific resources to reduce their risk. For instance, the FSWs requested free, high-quality condoms of many sizes; the MSM required better lubricant for anal intercourse to reduce injuries; while the IDUs wanted safety syringes and OST.

The FCS should regularly study programme guidelines and attend refresher training as a part of continuing professional education. The FCS should receive at least one training associated with the programme annually. This training can include behaviour change communication techniques and counselling skills on complex topics like emotional trauma.

Although HRGs wanted a distinct programme for their separate groups, they suggested conducting awareness campaigns to promote more acceptance of HRGs in society. They suggested that people should be aware that showing discriminatory behaviours towards anyone is a punishable offence. Additionally, MSM suggested that these campaigns should talk about the different sexual preferences of individuals and the decriminalisation of same-gender relationships.

FCS suggested that there were legal provisions to extract FSWs' contact information from brothels and hoteliers to extend programme benefits to them. They suggested mandating informal support groups for MSM and HTGs to register under the programme. They wanted these groups to operate alongside NGOs so that the benefits of safe sex advice and social networks could be extended to most MSM and HTGs. Many of these suggestions seemed unrealistic as they required a legislative order outside the programme's scope.

FFSWs who want to stop sex work and get regular jobs need education and employment opportunities through the programme. Some FSWs suggested skill-based training like IT, fabric sewing, typing, and beautician courses to access safer, socially accepted employment. Some FSWs requested support to establish small-scale businesses. Some design suggestions were of a broader nature that were beyond the programme scope. However, they were essential to state and analyse.

7.5.4. Delivering an HRG-Focused Counselling Programme Design (Destiny)

Several design suggestions were already part of HIV counselling guidelines; however, their implementation was not complete in the Una district. The NGOs involved with the programme must identify and understand the challenges and needs that HRGs face to design an effective counselling service (Tanwar et al., 2016). This programme should address social issues and focus on mental health, de-addiction, and rehabilitation for high-risk clients.

The programme can incorporate concepts around social role valorisation that involves recognising and valuing the contributions of individuals who may be marginalised or stigmatised by society. This can be incorporated into the counselling service by supporting clients at risk of prostitution in finding meaningful employment and building social connections in their communities. It may also include providing employment support for or developing programmes that help clients build social connections and find meaningful employment (Caruso and Osburn, 2011).

In addition, HRGs can be provided with a supported living model that involves helping clients find and maintain stable jobs and housing. This can be a crucial factor in helping clients reduce their risk behaviours similar to the one pointed out by Giangreco et al. (2001) for intellectual disabilities. Many HRGs have social challenges similar to people with intellectual disabilities which relate to the availability of appropriate housing, transportation, and other basic needs (Patel et al., 2013). The programme can provide support and referral services to high-risk clients, including assistance with housing, transportation, and other basic needs (Rao et al., 2014). However, due to the lack of sufficient resources and funding it is difficult to provide these services on a large scale (Rao et al., 2014).

The programme should involve clients in the design and implementation of the programme as they may have valuable insights and experiences to share, and even suggest better measures for the effectiveness of counselling. Equal importance should be given to counselling and behavioural change therapy in addition to HIV treatment and testing. Ongoing support and follow-up should be made available to ensure that clients can sustain changes in their behaviour. Techniques like a trauma-informed approach in the counselling service and specialised training should be made available for FCS on issues such as addiction, mental health, and trauma (Courtois and Ford, 2013).

The Delivery of an HRG-focused design, as suggested by CRs, will have its challenges. As discussed earlier, the programme faces funding and staffing challenges, making it difficult to implement comprehensive counselling and provide resources for living and employment support. Legal and policy barriers make it more challenging to create such a design as it criminalises certain behaviours or identities, making it difficult for programme officials to ask for funding. Besides that, misinformation, lack of awareness, and discrimination add to the complexity of challenges to implementing an effective programme.

7.6. Improving Data Sharing and Reporting Capabilities

Several challenges were associated with data sharing and reporting of progress by the NGOs at the Una district level. These were related to double reporting, non-sharing data from other districts, and lack of IT facilities. CRs also described NGOs' problematic reporting practices. An IDU coresearcher critiqued an NGO's double reporting.

> *If someone is lying here trembling with pain or hunger, a good man will come and give him some water or food for these NGO workers. It is more about attendance. They care about the number of people who are coming to them and giving their presence. The rest are left suffering. They will write five names of the people for attendance purposes. If I go into the NGO, they mark my attendance four times as they get a count of four out of me and can claim money for four people.* – Chela, IDU

Sometimes these practices created inaccurate, inflated data that compromised the integrity and reliability of the data, thereby undermining the programme's effectiveness. The IDUs complained that the NGOs only cared for those IDUs who visited them while many IDUs were left unattended. Nevertheless, they still double entries for inflating reports. The previously mentioned lack of IT facilities made it difficult to report data on time, highlighting the importance of maintaining and updating IT infrastructure to ensure the security and integrity of sensitive data. Furthermore, lack of data sharing from other districts made it difficult to get complete information about HRGs who relocated to Una.

7.6.1. Discovering Best Practices for Better Data Sharing and Reporting

CRs were asked to identify previous best practices regarding data sharing and reporting. One beneficial practice was for hospital staff to assist FCS in using their IT systems to upload data. By providing IT support and assistance to colleagues, the hospital staff helped FCS to ensure that data were reported timely. This was reflected as a culture of collaboration and teamwork, which can benefit the programme's overall functioning. Another discovery was that the FCS sought alternative methods to send reports, even without reliable IT systems and internet connectivity. Their method was to use computers in other rooms within the hospital or go to the local cyber cafe. However, this posed a risk to the security of sensitive patient data. The following section discusses what CRs dreamed about making the reporting systems more effective.

7.6.2. Dreaming for an Efficient and Confidential Reporting System

The FCS dreamed of having a reporting system that was efficient, user-friendly, and less labour-intensive for their programme. They hoped for a quick, comprehensive, and stored system to prevent double reporting and maintain client confidentiality. They wished for the authorities to take urgent action to create such a system for registered PLHIVs and HRG clients. FCS hoped for a reporting system that would allow them to effectively manage and control HIV infection in their district while maintaining the data sharing and reporting standards as prescribed by programme guidelines. The FCS also wished to receive more information about clients from other districts to maintain their continuity of care. They further suggested that a digitised system could store these HRGs' information to be tracked when they move places.

7.6.3. Designing an Effective and Digitised Reporting System

Besides providing an effective reporting system, digitisation at all levels was considered by the FCS as a tool for measuring staff accountability with ease. FCS suggested that the programme needs to digitise HIV counselling and testing-related data and ensure that the data are safely stored and shared anonymously and securely at all times in compliance with privacy protocols. The programme must adopt accurate data collection and reporting techniques that rely on standardised and integrated recording and reporting systems.

Considering that HRGs frequently move to other places, provision of a central and secure method of storing client contacts was believed to facilitate the delivery of nationwide continuity of care under NACP. However, it is counter argumentative. A national database is only successful if identifiable data are shared with the national public health database. Therefore, more important is to make sure that the staff adhere to patient data privacy and confidentiality policies.

FCS suggested a design that has better IT systems to support reporting processes and avoid multiple entries of the same information. This step was believed to reduce repeated reporting and submission of inflated reports by the NGOs. This system reduces the likelihood of tampering, with checks and balances to make staff accountable. They believed that such a system would stop NGOs from submitting inflated reports to satisfy officials, and thus increase the accuracy and rigour of the reporting process.

FCS imagined a documentation process that was quick and digitised using operational computers and an IT team to support any outages. FCS suggested that data should be stored behind authenticated staff login IDs and not be shared with other staff.

With this individualised access to HIV records, the authorities could track any sensitive data security breach. Alternatively, sharing counselling data with other hospital staff could be beneficial. For instance, if an itinerant person were admitted to the hospital and their health information stored in counselling data, this could aid hospital staff in better clinical care. FCS also suggested incorporating auditable barcode-based testing to stop privacy violations.

FCS suggested that the programme reports include qualitative perspectives and intermediate indicators showing implementation progress. They suggested that utilising qualitative reporting methods can give context to the reports. They argued that this would ensure that the HIV control programme is effectively meeting the needs of HRGs and making progress to reduce the impact of HIV on these populations. These elements should focus on the counselling and testing issues faced by HRGs.

Some examples proposed included indicators such as the number of new registrations, the number of post-test counselling missing words, medication adherence, and measures of stigma and discrimination faced by HIV-positive individuals while receiving programme services. FCS prioritised the qualitative aspects of counselling rather than merely the quantitative performance indicators. They believed that these changes could only be achieved when top management showed interest in the counselling services and improved its reporting processes.

7.6.4. Delivering a Secure and Respected Digital Platform as a Programme Design for HRGs (Destiny)

The programme can implement secure electronic health records systems to ensure that the personal information of high-risk clients is protected and not accessed by unauthorised individuals. For example, the EHR system implemented by the YRG Care HIV/AIDS Research, Treatment and Training Centre in Chennai includes measures such as password protection and access control to ensure the security of client information (Obermeyer et al., 2012; Sastry et al, 2004). However, implementing secure electronic health records may be challenging due to the need to invest in technology and infrastructure and ensure client information security and privacy (Obermeyer et al., 2012; Sastry et al, 2004). Storing sensitive patient data online carries the risk of data breaches or unauthorised access to information. Ensuring the security of digital systems and protecting patient privacy will be important considerations when implementing digital solutions in the HIV control programme in India (Privacy Commissioner, 2018).

HIV counselling programmes in several other Indian districts have offered online resources and support to HRGs including online counselling; support groups; and information about HIV prevention, treatment, and care. The use of telemedicine and online chat services can further improve the accessibility of the programme. Online communication with clients has also proven secure and private; for example, by using encrypted messaging platforms (Kihangire and Muhura, 2012). However, there may be challenges in Una related to the availability of technology, internet access, and telemedicine capabilities among certain populations and areas, as well as issues related to digital literacy (Ummer, 2021; Nittas et al., 2020). Ensuring the security and privacy of online communication with clients may also be challenging in India due to the need to invest in appropriate technology and infrastructure and ensure that client information is protected from unauthorised access (Ummer, 2021; Kihangire and Muhura, 2012).

Several district programmes have used social media and other online platforms to educate the public and HRGs about HIV with an aim to reduce stigma and discrimination. However, this may be difficult in Una due to the need to develop and implement effective social media campaigns and challenges related to the availability of technology and internet access among certain population segments (Hagg, Dahinten and Currie, 2018).

Moreover, as discussed in the management design section, some staff members may resist using new technology or may not be familiar with digital systems. This could create barriers to implementing digital solutions in the HIV control programme (Garg and Tiwari, 2015). Further, implementing digital solutions can require significant resources, including funding for hardware and software, training, and maintenance. These resources may be limited in the context of an HIV control programme in India (Lee, Liu and Lio, 2016).

7.7. Managing Workforce Challenges Related to the Programme

As highlighted in Chapter 5, section 5.3, the improper dissemination of the programme's funds has been a significant challenge to the effective delivery of the HIV counselling programme in Una. The funds for salaries, travel expenses, daily allowances, and accommodation expenses did not efficiently flow from the state to the district level and the NGOs. This resulted in a mismatch between what was promised to district employees and what was paid to them. A peer educator described a lack of transparency regarding the use of programme funds.

> *We are not aware of the actual politics that is going around in the programme. I do not know how much they are getting in lieu of the activities we are doing in the field. There is lack of transparency. We are not told how much they get for what we do in the field. For us, our salaries are only Rs. 3300 (USD 67) per month is the truth that we know, and the rest is unknown.* – Yog, FCS

In addition, the wages and other allowances paid to employees at the state level were significantly higher than those paid to employees at the district level, indicating a lack of fairness in the distribution of resources. The programme authorities failed to implement effective measures to ensure the unbiased transfer of funds and resources to lower levels of the organisation.

7.7.1. Discovering Best Practices Showing Staff Collaboration

When FCS were asked if they could identify past best practices or good examples that can be implemented in the future, they made a few promising discoveries. They expressed satisfaction with their job roles and the desire for increased compensation. The NGO staff showed commitment and continued working even without salary payments. They stated that it was necessary for their HRG clients as it maintained strong community liaisons.

According to a FCS, one NGO project officer demonstrated commitment to supporting the staff, going as far as to lend money for groceries when salary payments were delayed. This demonstrates a keen sense of community and collaboration. Peer educators have often paid clients out of their pockets to facilitate their counselling attendance. These efforts were often compensated by the NGO, demonstrating their investment in the programme’s success.

7.7.2 Dreaming of a Collaborative Work Environment

The FCS hoped the state would recognise and appreciate their work as field workers. They also dreamed of state officials taking account of their insights in community-based actions, particularly those working at NGOs. In addition, they wished for more timely funding for NGOs to improve their field activities and support the continuity of community activities. They hoped that with these resources, they could provide the best possible care to their clients and effectively manage and track HIV infection in the community.

The FCS also imagined a programme with more resources to support smooth day-to-day operations and better wages for FCS, paid on time. FCS from the HRG community desired less exploitative relationships with the NGOs they worked with and timely payment for their community services. They hoped for a programme to help build healthy relationships with the NGOs with whom they work.

7.7.3 Designing an Accountable Work Environment

FCS designed a programme where the state authorities demonstrated that they valued the intermediate programme outcomes and not just the district's KPIs that looked at client registrations, testing counts, and treatments. They proposed that the programme should be extended and that they should receive timely, regular increments and salary rewards to maintain their designated roles for an extended period. They also hoped to be granted additional roles in state programmes that required going to slum areas, such as sexual health and tuberculosis programmes. That way, the staff could better serve and network with their clients and provide backup for their contractual positions when their HIV programme funding recedes.

The CRs from NGOs requested more clarity on the distribution of funds and more timely payment of wages, as well as the convenient transfer of funds to NGOs. They also emphasised the importance of preventing bullying of FCS by senior staff, practised by making them work more, with threats of not paying wages. To address the issue of delayed salary payments, a source of staff attrition at the NGO level, the FCS suggested establishing an autopayment system for timely wages. In consideration of clients, CRs recommended prompt compensation to clients for their travel costs to get counselled and tested.

The CRs recommended creating a complaint suggestion and feedback box at counselling centres, managed by an external evaluation body that provides feedback on improving services without reprimanding staff unless necessary. They also recommended that the hospital staff whom HRGs recommended for their collegiality should be given some gift as motivation. They further added that respectful and courteous behaviour by hospital and frontline staff encouraged HRGs to attend regular counselling sessions.

7.7.4 Delivering a Programme Design with Coordinated and Trustworthy Staff (Destiny)

To deliver a programme with well-coordinated staff who trust each other, the following actions must be incorporated. The programme officials and FCS should develop clear communication channels and protocols for exchanging information and coordinating activities among staff. This can help to reduce misunderstandings and improve efficiency (Lam et al., 2016). The programme should organise team-building activities to build staff confidence and encourage collaboration and teamwork by creating opportunities to collaborate and share ideas and best practices (Un, Thai, De Munter, Lynen and Harwell, 2006).

Another worthy suggestion is to establish a feedback system that allows HRGs to provide input on the quality of care they receive, which can help identify any issues or concerns and address them promptly (Rowe et al., 2005). As complementary to feedback, recognising and rewarding staff for their contributions to the programme would also help foster a positive work environment and build morale.

The obstacles to delivering such an effective design would again be limited resources and funding for training and support to staff (Garrett, 2017). Some CRs may argue that higher levels of management would not prioritise improving staff coordination and trust (Lam et al., 2016). They may bring the past lack of transparency and accountability in allocating projects to NGOs as the reasons for mistrust and resentment among staff (Maiorana et al., 2012).

7.8. Developing a Programme With No Stigma and Discrimination to HRGs

In the Una district, stigma, discrimination, and social exclusion have been identified as common barriers to the HIV counselling programme. These issues have been particularly prevalent among HRGs, who often face negative attitudes and biases from society and hospital staff. One major challenge these groups have faced is the rudeness and misbehaviour of hospital staff, which has created barriers to accessing care and discouraged them from seeking HIV testing and counselling services. This has been especially problematic for IDUs, who have often been treated with disrespect or arrogance by hospital staff. Additionally, social exclusion has been a significant barrier to programme adherence among IDUs. These individuals have often felt marginalised or ostracised by society, which has made it difficult for them to access HIV prevention and treatment services. An FCS shared how difficult it is to talk with clients about HIV due to the associated stigma.

> *When someone comes to our room for counselling and testing, they are not encouraged to talk with us or listen to what we want to say. When we ask them if they do know about HIV and AIDS, they say 'yes'. They will say 'leave it' if we start telling them all about it. 'Do not tell us anymore. We know a lot about it, but we are not happy to hear anymore and do not want to do the test'. Much motivation engages in counselling and convincing that person to test. Because of the stigma and shyness, he does not communicate what he knows to us, and we have to tell them about the disease and its testing as a part of our job.* – Natu, FCS

FSWs have experienced a sense of powerlessness, which has made HIV counselling feel useless or ineffective. This has been compounded by fear of disclosure and social exclusion that many FSWs and MSM have faced, which has discouraged them from seeking counselling services. Furthermore, exploited MSM peer educators have been less supportive of the HIV programme, which has created challenges in engaging these individuals in prevention and treatment efforts. Addressing these challenges has been critical to the success of the HIV control programme and has required the implementation of strategies that support the empowerment of HRGs.

7.8.1. Discovery of Best Practices With No Stigma and Discrimination Towards HRGs

CRs identified a few best practices from the past that they believed could become the positive anchor for their Dreams and Design. FCS had demonstrated commitment to their duty towards their clients, even when faced with a power play from senior staff. They took steps to protect their well-being during stressful times as a commitment to self-care. Peer educators took initiatives for identifying and tracking clients, showing their commitment to meeting the needs of their community. However, during awareness activities, they were considerate of the needs of FSWs by keeping them unidentified. FSWs were open and willing to work with NGOs if their identities remained undisclosed. FCS respected their clients' autonomy and never forced them to disclose their identity or HIV status to anyone else, thus upholding informed consent and respectingd the agency of clients. This way, clients could make decisions about their health and relationships.

7.8.2. Dream of a Programme With No Stigma and Discrimination Towards HRGs

HRGs dreamed of a healthcare system where they were treated as regular patients without discrimination based on their social identity. They hoped hospital staff would respect their privacy by keeping their identity secure and not sharing any information with other staff or outsiders unless necessary. While they acknowledged the high workload at the hospital, they preferred appropriate behaviour that was not rude. In order to increase trust and improve the experiences of clients and FCS in the programme, FSWs wished for a zero-tolerance policy against discrimination. They believed this would help remove barriers to HIV counselling and encourage HRGs to adopt preventive behaviours.

The CRs hoped the programme would help increase awareness in Una society, leading to greater acceptance of HRGs within the community. FSWs dreamed of a society where their customers consistently practised safe sex, and they desired the programme to educate the community about the risks associated with unprotected sex. These wishes reflected a desire for a more supportive and informed society where all individuals can access quality healthcare and make informed decisions about their health and well-being.

7.8.3. Designing a Programme With No Stigma and Discrimination Towards HRGs

When designing a counselling programme for district Una, CRs proposed various practical strategies for the social support of HRGs and creating a zero-tolerance policy against discrimination. One strategy involved revising counselling guidelines to reduce stigma and discriminatory practices by staff members; incorporating updated information on HRG behaviours, classifications, and needs. To create a more welcoming environment, they recommended the creation of separate waiting areas for HRGs and PLHIV clients, and urged NGOs to avoid accompanying HRGs in a way that could be easily identifiable.

The CRs proposed a zero-tolerance policy against discrimination. They also advocated for stopping the practice of putting the “star dot” label on HIV positive clients’ paper files to identify their HIV status. Strict action should be taken against staff members who disclose client information to unauthorised individuals. They also proposed using a feedback box for HRGs to share their complaints and suggestions about programme activities and staff conduct.

FCS suggested the creation of a staff code of conduct tailored explicitly to HIV counselling for HRGs and their unique identities. This code will promote respectful conduct towards HRGs and include provisions such as a cap on maximum wait times. FCS also suggested the creation of enrolment cards for registered HRGs to support HRGs and staff IDs for NGO staff to facilitate easy interaction with the HRG community. FCS also proposed the establishment of a code of conduct between authorities and staff members to focus on staff bullying and disrespect issues.

CRs also suggested implementing accurate community needs assessments and creating detailed project proposals with accompanying budgets before allocating any community projects to the NGOs. This would involve showing accurate community linkages and demonstrating the capacity to deliver services.

7.8.4. Delivering a Programme Design With No Stigma and no Discrimination (Destiny)

The CRs shared several design strategies for a zero-tolerance to discrimination-based programme; however, multiple requirements were identified when delivering them. Implementing such a design required training hospital staff on the importance of treating all clients with respect and dignity, regardless of their HIV status (Pachankis, 2007; Stephen Ekpenyong, Nyashanu, Ossey-Nweze and Serrant, 2021). The authorities need to establish clear anti-discrimination guidelines and policies that outline the behaviours that are not acceptable in the hospital (UNAIDS, 2022). They need to ensure that guidelines are widely disseminated to all staff. The CRs added that the hospital staff who violate these guidelines should face consequences, such as termination or suspension, depending on the severity of the offence.

In order to reduce stigma and discrimination, the programme can educate the community about the importance of confidentiality and the rights of HRGs, including

HIV-positive individuals in Una (Patel et al., 2013); although this could be difficult in Una due to the prevalence of negative attitudes and beliefs about HIV and HIV-positive individuals (Patel et al., 2013). There may also be challenges related to the lack of awareness about HIV and HIV-related issues in the Una society (Nyamathi et al., 2011). Further, social factors such as traditional attitudes towards HIV would contribute to the difficulty of implementing these policies (Patel et al., 2013). The traditional attitude of society to stigmatise HRGs supersedes the legalities of privacy policies that advocate a non-discriminatory behaviour.

The programme needs to invest in community education and outreach efforts to increase awareness about HIV and reduce stigma in the community (UNAIDS, 2022). This can include working with local organisations, schools, and community groups to provide information and resources about HIV prevention, treatment, and support. It can also work alongside local law enforcement to protect high-risk clients from violence and discrimination (Human Rights Foundation, 2021.). This would involve training police officers on how to respond to incidents of discrimination against HRGs of Una.

Apart from the lack of resources and legal barriers, the obstacles to implementation were similar to other discussions on delivering design suggestions. Some staff members may not realise the importance of treating clients with respect and dignity. Others could resist new policies or guidelines, particularly if they feel that they are being asked to change long-standing behaviours or beliefs. In some cases, legal barriers may prevent hospitals from implementing certain policies or programmes, such as laws protecting the confidentiality of medical records. Without adequate support from the hospital and the community, it would be difficult to effectively educate the public about HIV and reduce stigma.

In conclusion, implementing an effective design for a HIV counselling programme can be achieved through various strategies, such as clear communication, zero discrimination, and providing training. However, there may be challenges that need to be addressed, such as limited resources and funding, resistance to change, and lack of support from higher levels of management. HIV programme needs to address these challenges in order to create a positive work environment and improve the quality of care for HRGs.

7.9. Summary

The above sections explored the perspectives of CRs, retracted from their drawings and FGDs related to their dreams of an effective HIV counselling programme and how they designed it for the Una district. The content depicts key moments of co-constructing dialogue for building the images of a shared future where CRs implement an effective design for HIV counselling programme through a variety of strategies, while also discussing the challenges that need to be addressed.

CHAPTER VIII – DISCUSSION AND CONCLUSION

DELIVERING AN EFFECTIVE HIV COUNSELLING PROGRAMME

8.1. Introduction

This chapter discusses the key findings in light of the research question, “How can the HIV counselling programme delivered in Una district, Himachal Pradesh state, northern India, be made more effective?” The first sub-question explored current knowledge about the evolution of the Indian HIV programme and how that has shaped how its effectiveness is measured. As the empirical part of the study, research sub-questions two and three focused on engagement with the CRs as a means of exploring the effectiveness of the HIV counselling programme through their lens. The chapter starts with an overview and summary of the main findings, followed by design suggestions by the CRs and discussions on the methodological implications. The section ends with recommendations for the Indian HIV counselling programme, a suggestive model for programme implementation, and an overall conclusion.

The study findings have implications for transformed approaches to addressing the challenges faced by HRGs when accessing the HIV counselling programme in Una. Policy and programme recommendations include the need for a more contextualised and social determinant-based approach, promotion of indigenous ways of counselling, and inclusion of CRs’ perspectives in planning, development, and operations. The study contributes to the growing body of literature that uses AI as a methodology and examines the issues of people at risk of, or living with, HIV/AIDS; and paves a valuable path towards a culture of transformation and creating an environment for positive change.

8.2. Overview of the Study

The following sections summarise the situational analysis of the HIV epidemic (Chapter 2) and the historical and policy context for the Indian HIV counselling programme (Chapter 3). The summary of Chapter 2 revisits the discussions on epidemiological patterns of HIV in India and Una and the examination of social profiles of HRGs. It also re-evaluates the literature on HIV counselling programmes and the overall public health response to HIV in India. The summary of Chapter 3 re-examines the impact of pre- and post-colonial events and the effectiveness of the programme as it has evolved over the years.

8.2.1. Summarising Situational Analysis of HIV Epidemic in India and Una

This section summarises Chapter 2 – the situation analysis of the HIV epidemic in India and its spread within HRGs of the Una district. In addition, it summarises India’s public health response to the HIV epidemic with specific reference to the HIV counselling programme. The situational analysis described in Chapter 2 positioned the epidemic in Una in relation to the epidemiological patterns of its neighbouring regions and India as a whole. This was followed by a specific focus on HRGs in Una and their social and economic context and behavioural profiles. Towards the end of the chapter, the situational analysis critiqued how the HIV counselling programme’s effectiveness is measured and the programme’s position in a broader public health response to HIV in India.

Over the years, the prevalence of HIV within HRGs has consistently been higher than in other population group (Ramachandran, 2012; UNAIDS, 2018). The main reasons for the higher HIV prevalence in HRGs have been identified as unprotected sex, especially anal sex, with multiple or concurrent partners or with partners who have multiple or concurrent partners; and the use of unsafe needles and syringes for drug use

(UNAIDS, 2003, 2018). Hence the continued need for effective HIV prevention and counselling programmes for HRGs, and the importance of addressing social determinants of health, such as stigma and discrimination, that may limit access to these services (NACO, 2007c).

HIV counselling programme for HRGs has been designed to prevent new HIV infections and post-infection complications in this population (NACO, 2007a). The programme activities focus on increasing counselling and testing services, improving access to HIV diagnosis and treatment, and providing an entry point for HRGs to access these services (NACO, 2015d, 2017c). This approach has effectively controlled new HIV infections within both HRG and non-HRG populations, as the latter group is at higher risk of infection due to high-risk activities like transactional sex with HRGs or drug injection (National Sample Survey Office, 2014). However, the programme overlooks qualitative aspects of programme effectiveness (Limb, 2011; Patil, Somasundaram and Goyal, 2002) making it difficult for the programme to attract resources from the government, which can lead to reduced funding and negatively affect the lives of HRGs (Avert, 2014).

The HIV counselling programme for HRGs, in particular, has faced challenges in accurately assessing its impact due to a lack of focus on social and organisational factors that can influence the effectiveness of the programme (NACO, 2014). Programmes must be evaluated using quantitative and qualitative performance indicators to measure their success. The existing evaluations neglected to report the perspectives of HRGs and FCS, resulting in less appreciation and support for the programme (NACO, 2014). However, this AI study undertaken with HRGs and FCS has provided valuable insights into how the programme can be made more effective by taking into account the power dynamics and social factors that impact the programme.

8.2.2. Insights From a Literature Review of HIV Counselling Policy

This section emphasises the need to consider historical interactions and social structures influencing the programme's effectiveness. It summarises Chapter 3, which discussed the historical and policy review of the effectiveness of the Indian HIV counselling programme. This critical policy analysis revealed historical interactions that impacted the programme while, simultaneously, showing how social structures influenced the programme's effectiveness. The chapter explained how the Indian HIV counselling programme evolved and how its programme effectiveness was shaped.

As pointed out in the above section, the HIV counselling programme has mainly utilised quantitative methods of measuring effectiveness, neglecting the qualitative aspects of public health effectiveness, and showing the domination of the mainstream biomedical treatment system. While the literature on HIV counselling programmes' effectiveness is undoubtedly valuable, a closer examination reveals potential gaps, assumptions, and areas that might benefit from a more grounded and context-specific approach.

Effectiveness studies involving interpersonal therapies for HIV prevention have shown higher adherence to prevention and treatment (Padmapriyadarsini et al., 2020) in comparison to usual care. When added with behavioural strategies, these changes were more significant and sustained in at-risk individuals (Coates, Richter, and Caceres, 2008). However, such approaches require multiple communication channels and has been found to be too ambitious, especially in settings with limited resources. The proposed amplification of behavioural strategies by targeting multiple objectives and multilevel approaches, spanning from couples to entire communities, could be logistically challenging and risk diluting the core message.

Another multifaceted approach, the health promotion-based effectiveness strategy, uses STD rates and fertility changes as primary indicators, which was again found not to be the most reliable approach, as many external factors can influence these metrics and appear to lack cohesion (Coyle et al., 1991). In comparison, the US Health Resources and Services Administration's (HRSA) (2002) effectiveness strategy is inherently more subjective and can vary widely based on individual and cultural contexts. Along with other behavioural indicators, the HRSA monitors symptoms like anxiety or depression after a positive HIV test result. However, the strategy's increased focus on monitoring treatment can be influenced by various external factors, including drug availability, healthcare infrastructure, and socioeconomic conditions.

Mainstream public health programmes often ignore indigenous health paradigms. It measures effectiveness intrinsically and neglects the achievements of the Indian system of medicine. Ignoring the social factors of Indian HRGs indicates a missed opportunity, leading to the programme's ineffectiveness in achieving desired public health outcomes. Locally strengthened public health systems that consider the social factors of HRGs can contribute more to contribute to the HIV counselling programme.

The HIV epidemic is not merely a public health problem for India but has impacted the country's economic growth (Oja and Pradhan, 2006). The ambition of economic development in a resource constrained environment has forced the Indian government to spend less from public funds and rely primarily on donor funding for the HIV programme. The programme has been left with no other option but to operate with these limited resources delivering services that are not effective in controlling the epidemic. The Indian HIV programme has failed to control HIV due to limited resources, ignorance of social factors of HRGs, and the concentrated nature of this epidemic.

In post-independent India, there has been a marked shift from government-regulated integrated public health to disease-specific programmes shaped by international donors. Measurements of programme effectiveness have shifted from being health-centric to business-centric, depicting a neoliberal model of public health that focuses on achieving cost efficiency (Tulchinsky and Varavikova, 2014). The programme's over-reliance on quantitative methods of measuring effectiveness and a bias towards allopathic treatment has neglected local perspectives and the contributions of locally strengthened public health systems that consider HRGs social factors. Ignoring social factors has led to the programme's ineffectiveness in achieving desired public health outcomes, contributing to the HIV epidemic's economic impact on India.

In conclusion, the global literature on HIV counselling programme effectiveness, while extensive in its quantitative metrics, seems to overlook the depth of qualitative methodologies. The evaluation of these programmes predominantly hinges on tangible outcomes, such as delaying first intercourse or increasing condom use, without delving into the socio-cultural and economic dynamics that influence these behaviours. Their reliance on quantitative indicators, such as the prevalence of STDs or prescription rates, does not capture the deeper societal narratives, power imbalances, or structural challenges individuals might encounter. While these quantitative techniques offer valuable insights, they lack the critical interrogation of underlying structures and dynamics that a qualitative approach rooted in critical theory provides.

8.3. Discussion of Main Findings

The three results chapters discussed several factors that affect the implementation and success of HIV testing and counselling programme in Una. First, the organisational and management factors, which include the issues raised by CRs concerning the resources and infrastructure required, and policies and procedures necessary for the effective operation of the programme, were examined. Next, the social factors that impact the programme that can affect the accessibility and uptake of these services were attended to. Finally, the findings explored the “4Ds”—Discovery, Dream, Design, and Destiny—the framework used to guide the development and implementation of effective HIV testing and counselling programme. The 4Ds provided a structured approach to identifying needs, evaluating the impact of factors, and developing strategies for improving the counselling programme. This framework is an innovative approach to planning and implementing an HIV testing and counselling programme, which ensures that the programme is tailored to the specific needs of the communities in which they are implemented.

The CRs discovered the existing strengths and dreamed of a programme without organisational and management barriers. The Design for an effective programme focused on abiding by the revised programme guidelines and making structural changes to the counselling and testing rooms to make sessions more private. The ideas for Destiny were extrapolated from the first three stages. The design implementation in the actual setting has been discussed in parallel with prevalent organisational and socio-political factors that may impact the programme.

8.3.1. Summary of Organisation and Management Factors

This results chapter answered the second and third research sub-questions that focused on exploring the effectiveness of the HIV counselling programme through CRs’ lens and proposing strategies to improve the programme. Among management factors, privacy issues were highlighted as the first challenge in delivering an effective HIV counselling programme in Una. Lack of privacy discouraged clients from getting tested or returning to the counselling centre to collect their test results. Furthermore, the programme lacked provisions for delivering private counselling sessions and did not have a digitised client data management system which made it challenging to store and share client information securely.

Another challenge was related to delays in attending the counselling programme, especially when clinicians refused to treat HRGs due to HIV status. Due to long waiting times, several HRGs were forced to leave without treatment. The registration process for getting services under the HIV programme involved lengthy documentation. Sometimes doctors and nurses declined to serve them after they were identified as HIV positive, delaying the process further for HRGs. Many times, HRGs had to wait long hours, resulting in many HRGs losing their daily income and making them more vulnerable to poverty.

One critical management and organisational factor influencing the decision to join counselling and testing was that the services were not open during convenient hours. The centre only operated during business hours (9am to 5pm) and not in the evenings. Often this was inconvenient for HRGs as the opening hours of the counselling services did not accommodate their work lives. As HRGs often have poor financial security, even a few absences from work could pull them (and sometimes their households) into poverty.

The CRs reported the counselling solely discussed HIV prevention and prepared HRGs for the test. It lacked any mental health support for the HRGs. Although the counselling guidelines stated that psychosocial support should be provided to HRGs wherever necessary, it was not a part of regular HIV counselling practice in Una. The CRs stated that HIV counselling should have a broader scope in providing psychological support to HRGs of HIV in Una and should not be limited to prevention advice.

Some CRs employed at the NGOs expressed that they were unsettled by the authorities' lack of appreciation of their efforts towards changing the risk behaviour of HRGs. The discussions revealed that the district authorities did not recognise the breadth and complexity of the work done by FCS at the community level. The FCS directly impacted their clients' lives through HIV prevention, but their efforts were neither appreciated by these authorities nor captured in their reports.

HRG clients discussed how trust was vital for successful HIV counselling services, which can be maintained through continuity of care. They stated that staff turnover might be attributable to the interrupted flow of funding that hindered the continuum of care. These disruptions led to the HRGs losing trust in FCS's commitment to delivering care.

Other management and organisation factors are the challenges in implementing the programme due to non-cooperation by hospital authorities, bureaucratic challenges in the flow of funds, ineffective reporting processes, inadequate adherence to programme guidelines, lack of state resources, and inadequate appreciation of HRGs' lives. AI discussions also revealed that the CRs witnessed a lack of transparency in finances and distribution of funds related to the programme at higher levels.

The counselling sessions conducted under the programme did not conform to the programme guidelines (NACO, 2007a). As the number of clients coming for testing was so high, the counsellor could not deliver even a 5-minute pre-test counselling session to each client, let alone the 20-minute standard. Only a few clients attended post-test counselling sessions; however, they were reported separately. Instead, post-test counselling was reported combined with the pre-test counselling sessions. In most cases with negative HIV test results, no counselling was undertaken. Negative results were not even conveyed to the clients unless they enquired by phone or revisited the centre for their results.

The second implementation issue was the absence of a female HIV counsellor. The guidelines recommend appointing an additional counsellor where more than 500 individuals get counselled in a month or when the clients demand a counsellor of their gender (NACO, 2016a). However, the state did not fulfil such requirements for the additional workforce even after repeated client demands, showing a gross breach of standards.

The CRs stated that programme reporting in the Una district was labour-intensive, time-consuming, and ineffective. The time-consuming reporting system resulted in missed communications and repeated reporting, thus further increasing the staff's workload. CRs added that the state had overlooked the resources required for programme reporting, such as IT and database management, and these issues were easily solvable.

To summarise, the organisational and management factors impacting the programme for HRGs included organisational challenges due to lack of privacy issues and certain discriminatory practices by hospital staff. Other issues related to the organisational structure were long waiting hours, non-consideration of HRG demands for gender-matched counselling, and the programme's inflexibility in providing services at HRGs' convenience. At the same time, implementation challenges included a limited workforce, inadequate compliance with programme guidelines, and a lack of transparency in processes.

8.3.2. Summary of Social Factors Affecting the Programme

The following summary discusses the social factors in the context of stigma, discrimination, and social abandonment of HRGs. It discusses the inhibitors to HRG's decision to get counselled that were mainly associated with stigma and discrimination from hospital staff and the programme's inefficiency in capturing the unique identities of HRGs. The HRGs reported experiencing disrespectful and offensive behaviour from hospital staff based on their appearance and HIV status, discouraging them from seeking counselling services. Furthermore, due to societal disapproval of homosexuality in Una, MSM expressed a need for confidential and accessible counselling services to avoid discrimination from their families and the general public. In Una, some FSWs avoid attending the programme to prevent disclosing their identity and potential stigma related to HIV. Some even denied their HIV-positive status after infection. These findings suggest a need for improvement in the delivery of counselling services for marginalised populations in Una to ensure they receive the support they need in a safe and non-discriminatory environment.

The peer educators who acted as coresearchers reported mistreatment by the NGO staff. Their role involved bringing clients from HRGs to counselling centres and receiving a minimum wage for each client. The payment, which barely covered travel and food expenses, was frequently delayed, causing frustration and discouragement among the peer educators. This misconduct led to a decline in their outreach efforts, highlighting the need to better treat these individuals in the HIV/AIDS response.

The programme did not understand the unique features of HRGs. Consequently, HRGs were less willing to seek counselling. In some respects, the programme failed to include regional diversities of HIV transmission methods and characteristics of HRGs. Like any other north Indian district, Una harbours a conservative society where religion opposes homosexuality, power within relationships is unequal based on gender, and HIV is considered a morally charged infection. The social taboo related to HIV infection was a critical factor discouraging HRGs from attending the programme. The expression of homosexuality in Una was also complex, but the programmatic definition of MSM also did not capture one’s sexual identity in situations where sex was not only with a male but also with a transgender person (*hijra or kinner*). The FSWs who lived in these slum clusters, referred to as *bhabi,* were unique due to their practice of solicitation. Nevertheless, this typology of FSWs was new to the classification given by NACO (1997) and the one reported by Buzdugan et al. (2009).

Una has an immense plurality of followers of conservative ideologies, reflecting the wider Indian society. The social factors were multi-dimensional and interlinked to a combination of factors, such as unemployment, lack of skills, low income, poor housing, and ill health. The programme did not give importance to these peculiarities and needs of HRGs while delivering counselling services. Further, the programme did not show any efforts to preserve traditional social institutions or attribute drug addiction to religious devotion, thus not giving importance to this attribution of HRGs while delivering counselling services

8.3.3. Summary of the AI Process—Discovery, Dream, Design, and Destiny

This section summarises the strengths of AI methodology adopted by CRs that resulted in narratives at three stages: Discovery—examining the past strengths of the programme; Dream—examining CRs' visions for an effective HIV counselling programme; and Design—examining how they would design it for the Una district. Destiny was the stage where the design's feasibility was critiqued.

Broadly, the discoveries, dreams, and designs related to mitigating the challenges raised in programme designing, implementation, and organisational practices. CRs focused on enabling more HRGs to get counselled and tested; thereby reducing their vulnerability to HIV infection. These narratives derived from the 4Ds are particularly noteworthy as they highlight the problems and solutions proposed by 30 coresearchers—15 FCS and 15 high-risk individuals—who participated in this research on improving the HIV counselling programme at Una district.

The CRs demonstrated a pragmatic approach informed by their experiences to recommend solutions for improving the programme's effectiveness. Despite initial discussions hinting at impractical and ambitious ideas, their suggestions effectively presented practical solutions when given a chance to propose or initiate change. One may argue that practical suggestions do not necessarily tackle the issues at the level of paradigm. Therefore, a transformative model for the health system has also been suggested at the end of the chapter.

The emergent themes from FGDs and drawings offered valuable insights into realistic and appropriate solutions for the challenges faced in the programme; solutions that could be easily considered, adopted, and promoted by stakeholders in the fields of public health. But considering there is a lack of funding for the indigenous public health system, it can be argued that such solutions could contradict this complex and intransigent situation and may end up in a similar situation for the programme at a later point.

For design, drawings were used to generate ideas, and participants were encouraged to narrate these ideas. Destiny would require evaluating the ideas developed during the Design stage on the ground. Destiny asks to put the Design plan in place. It requires the plan to be evaluated on the ground and then optimised accordingly. It is important to understand that AI is a management tool. When participants visualise what was best in their organisation in the past, that is the first step to initiating positive change.

8.4. Methodological Implications

AI is based on the premise that all stakeholders should have a voice in the change process and that the collective wisdom and experiences of the group can be leveraged to identify and amplify strengths (Cooperrider and Whitney, 2005). However, this participatory approach may not be sufficient to address power imbalances or issues of social justice, particularly in situations where there are significant differences in power or privilege between stakeholders (Bushe, 2014). In such cases, it may be necessary to address power imbalances and incorporate approaches or frameworks that focus specifically on social justice issues (e.g., critical theory). When put in a critical space, participants describe their problems before coming to positive strength-based suggestions for improvement; which usually happens when the participants are not allowed to discuss them beforehand. The section captures how AI can help extract ideas for developing strategies for improving the programme's effectiveness.

Additionally, AI may not be well-suited for improving organisations with a culture that is heavily focused on problem-solving or resistant to change (Hatch, 2002). This situation resulted in CRs giving negative responses or describing challenges they faced in implementing the process. The use of AI in India faced challenges due to the country's cultural orientation towards problem-solving, especially in public organisations. India has a long-standing culture of bureaucracy that is typically resistant to change, which can make implementing new processes challenging (Chakrabarti et al., 2021). AI's focus on positive affirmations and collaborative problem-solving may not always be welcomed by public officials who may feel more comfortable with a top-down approach to decision-making (Bhamra et al., 2011).

Furthermore, India's diversity of cultures and languages may present additional challenges for implementing AI. In a country with over 22 official languages and numerous cultural variations, it can be challenging to find a common language and shared values that all participants can agree on (Mukhopadhyay and Chakraborty, 2018). Despite these challenges, AI has been used effectively in various sectors in India, including healthcare and education. For example, AI has been used to improve maternal and child health in rural areas of Maharashtra state (Zakirhusain and Chavan, 2017); and has been used in education to transform schools and promote positive changes in teaching practices (Kumar and Chako, 2012).

With restricted access to the programme staff prior to research ethics, limited literature on the district, and restriction of overseas travel, a limited understanding of the

HIV programme in Una was gained before the fieldwork. This understanding was based on a brief unofficial meeting with the district counsellor and CMO, who gave me some ideas on the struggles with the counselling programme and broader issues that resulted in the programme's ineffectiveness such as lack of funds, workforce, clients unhappy with the services, overworked staff, and bureaucratic hurdles. Based on this understanding, and the associated literature from other districts, I was able to argue that counselling needs to be improved. Due to the critical nature of the research settings where power imbalance was observed between the funders and staff, AI was considered the best strength-based approach to find solutions in a participative manner. Hence, FGDs sought to ascertain what was best in the programme in the past, what the participants dream of its future, what the plans are to achieve it, and how they see it in real settings.

When the traditional 4D AI model was applied in the complex public health setting of the Indian HIV counselling programme of Una district, the Discovery stage was unable to identify the best in the programme. Instead, out of 31 hours of audio recordings, 20 hours presented the issues and only 11 hours discussed reinforcement of positive and generative philosophy. The discussions had to be returned to the positive thread in all stages, keeping it steered to the best in the organisation.

Cooperrider's 2020 blog on the pandemic talks about such situations, which he called challenges of "broken worlds", where participants have difficulty identifying a "positive" from the past. However, reflecting on these challenges does help in asking the right question that can assist CRs imagine a positive future, as in the current research.

In these 20 hours, participants succeeded in reflecting on the programme's challenges that have remained unaddressed for several years. The interpretations of these 20 hours became the results of Chapters 5 and 6, which primarily focus on the issues found during the discovery phase of FGDs. Further analysis shows that the discovery phase allowed frustrated FCS and clients to talk about the programme's ineffectiveness. These discussions provided insights into what areas need to be targeted to get a positive future. Due to its participative nature, AI allowed an elaboration of the context during the Discovery stage that helped define the questions much more clearly before the next stages.

Chapter 7 analysed the 3Ds—Discovery, Dream, and Design. The challenge of the Discovery phase was that the CRs could not discover the positives from the past. Finding a positive core that steered the programme was challenging for them. Although the Discovery phase required CRs to find the best of what has happened in the past, they could not do so due to the reasons associated with the programme's ineffectiveness. The HRGs with HIV infection rarely lived for long. On the one hand, social factors were relevant, such as social exclusions, stigma, and discrimination. On the other hand, the programme was impacted by organisation and management factors such as interrupted programme funding, lack of testing kits, reduced adherence to prevention and rehabilitation provisions, and interrupted supplies for HIV prevention and treatment.

The HRGs who participated were either new to the programme, were newly diagnosed HIV positive, or were recently enrolled. A few HRGs who have been with the programme for a long time did not participate in FGDs due to stigma and discrimination. The FCS were even worse with respect to engagement in the programme. Only four of the 15 counselling staff had regular contracts with the HIV programme, while others were newly contracted within the past 2-years. Many workers had left their job due to low pay, delayed wages, and instability of contracts. Three months delay in payment of NGO-based FCS was typical for the NGOs.

AI is a management-oriented exercise and was not originally designed for research purposes. This research has been tried on the Una district's HIV counselling programme, where such strength-based methodologies are relatively untested; and, historically, such techniques have only been used to instil leadership skills for training in the business context (Cooperrider et al., 2008). When Cooperrider and other AI practitioners tried this methodology in organisational settings, it was used to bring change to pressing challenges impacting the organisation (Whitney et al., 2010). The outcome of this research is not to develop new AI version as a research tool for complex situations, such as the Indian HIV counselling programme, but as a case study showing the challenges AI may face when executed in such settings. It is to critique if there is a need to adopt a different approach to apply AI in public health research where the participants get space to speak about their issues and are allowed to think of the best in the organisation.

8.5. Significance of Research

This study stands out as a unique effort to improve the effectiveness of an HIV counselling programme in the Una district by utilising AI participatory research methodology. The study takes a user and provider-centred approach to understand the experiences and perspectives surrounding HIV counselling. by involving individuals who are voiceless and powerless power as CRs—FCS and HRGs. The research creates a creative, narrative space for participants to express their perspectives utilising AI methodology through FGDs. This study offers a philosophical framework rooted in critical theory that critically examines the experiences and perspectives of the CRs, making it a significant contribution to the field of public health.

The significance of this research extends beyond the realm of HIV counselling to the broader issue of participation and representation of HRGs in the reform of public health programme design and implementation. The increasing health needs of HRGs, particularly those related to mental health, highlight the widening gap between biomedicalised, treatment-centric approaches to public health. The findings of this research project are a poignant reminder of the poor counselling outcomes faced by HRGs in Una, including the highest rates of transmission and delays in service delivery highlighted by several HIV research studies. By utilising a participatory research approach, and a critical approach towards evaluating programme effectiveness, this study offers a unique opportunity to intensify the perspectives of clients and frontline staff in the public health system of Una. Given this opportunity, these ideas could be used to shape policy and practice rather than limited to providing solutions for the current problems with the programme.

By utilising participatory and critical research approaches to evaluate programme effectiveness, this study uniquely expressed the perspectives of clients and FCS in India’s public health system. This approach is crucial in addressing the power imbalances and structural barriers that have historically excluded HRGs from meaningful participation in decision-making processes related to their health and wellbeing (Guta, Flicker and Roche, 2013). It also highlights the need to move beyond a neoliberal cost-efficiency approach to public health and, instead, prioritise community-driven approaches grounded in human rights and social justice principles (Tulchinsky and Varavikova, 2014).

The importance of including HRGs’ voices in HIV research, policy development, and evaluation is increasingly recognised globally. This research exemplifies how FCS and clients can act as allies by using participatory methods to diminish power differentials and keep the focus on their improved health outcomes. This study illuminates the power of AI, which is brought to the forefront, demonstrating how it amplifies the voices of FCS and HRGs and enhances their ideas. Utilising such creative methodology, this project offers a tangible example of how participatory research can produce meaningful understanding that puts HRGs’ needs at the centre. As such, this project represents a valuable contribution to improving HIV counselling programme effectiveness in Indian public health and serves as a model for greater inclusion of HRGs' perspectives from the community.

In conclusion, this study underscores the importance of a critical and participatory approach to public health research and programme implementation, particularly for marginalised populations such as HRGs. By strengthening the voices of HRGs and foregrounding their experiences, this approach can lead to more effective and equitable public health interventions that address the structural determinants of health and promote social justice.

8.6. Study Limitations

While AI was applied in this research with the intention of eliciting CRs' perspectives towards the HIV counselling programme in Una, several limitations were identified by the end of the study. The first few limitations related to CRs' preconceived notions. The FCS were anxious about how change was perceived and whether it would bring more responsibilities to them. They felt that the process was not aligned with the programme's culture of problem-solving; lacked strength-based approaches such as AI; and ignored acknowledging the power conflicts, underlying issues, and personal emotions.

Talking about change was difficult. At the beginning of FGDs, some CRs resisted the AI process due to fear of the unknown or a desire to maintain the status quo (Whitney and Trosten-Bloom, 2010). This resistance manifested in unfavourable responses or feedback during the AI process. CRs were unfamiliar with the AI process and did not understand how it was intended to work. Some even felt that the research methodology was not aligned with what they had seen as the programme's culture, which was heavily focused on problem-solving (Hatch, 2002). Some were not invested in the AI process (Whitney and Trosten-Bloom, 2010) as they felt it ignored the presence of fundamental challenges that need to be addressed (Hatch, 2002). They felt that the process was driven by organisational politics and resisted it (Whitney and Trosten-Bloom, 2010). Finally, after much convincing, rapport building and creating space for the negative responses, CRs participated in the AI process.

AI is a positive, strengths-based approach to organisational change and development that focuses on the positive aspects of a system or organisation rather than trying to fix problems or deficiencies. AI is not designed to address underlying problems. Instead, its process is focused on finding positive and strength-based solutions and does not adequately address deeper, underlying problems or issues that may be present in an organisation or have unrealistic expectations (Whitney and Trosten-Bloom, 2010).

Recurring complaints were that counselling was not prioritised in the health system and lacked funding. Similarly, IDUs had unrealistic expectations from the programme that their OST dosages should be increased, which could lead to health issues. When asked to move on to the following issues, some CRs felt disappointed and disconnected from the process. As the HIV counselling programme was a relatively low priority within the Una health system, CRs believed there was limited buy-in or commitment from leadership to improving it (Whitney and Trosten-Bloom, 2010). For instance, an IDU invited to a second FGD did not join as he was not expecting a positive outcome. He did not feel a sense of ownership or empowerment in the research exercise.

Other limitations were related to the scope and applicability of the chosen research methodology. It was observed that the positive questions were not fully applicable to the issues related to the HIV counselling programme at Una district. FCS were more interested in questions that expected more solutions-based responses (Gray, 2013), such as reasons for a delay in wages and reasons for discrimination of HRGs. The methodology relied on collecting and analysing data open to interpretation (Gray, 2013) which made it challenging to draw firm conclusions. Therefore, repeated listening to audiotapes and rigorous transcribing were required to ensure rigour of data, so the emergent themes were credible and valid. The process of translating and transcribing mixed dialects into English (Gray, 2013) from three Indian languages was time-consuming and challenging to analyse.

AI has been criticised for not being suited for studying complex systems (Gray, 2013). Its process is modified for every organisational setting, which makes it difficult but constructive for use in diverse public health programme contexts (Gray, 2013).

Further limitations were that I was new to AI, and it was my first actual AI exercise after a test session with a colleague at the university. AI requires detailed planning and pre-preparation of participants, which was achieved in a limited capacity due to overseas travel, local approvals, and a limited period for data collection (Whitney and Trosten-Bloom, 2010).

As the last segment, applying AI methodology in the public health thesis missed an essential component of the AI process: implementing the design in real settings. Design suggestions did not reach their destiny because the summary of findings can only be sent to the participants once the thesis is complete. Additionally, I faced considerable delays in submitting the thesis due to full-time employment, personal health, family-related issues, and pandemic delays. From the aspect of the suitability of AI and participatory research approaches in the Indian context, I believe that there is a strong association between Indian public health and spirituality, biomedicalised public health, and the decisions being strongly impacted by hierarchy and power. Therefore, any critical approach can be applied in Indian settings, provided they give due importance to these factors.

8.7. Impact of the COVID Pandemic on the Frontline Workers of India

The COVID-19 pandemic has had a profound impact on the health workforce globally. In India, the pandemic has exposed deep-rooted challenges in the health system and the need for a radical change in healthcare delivery. No study has evaluated the impact of COVID-19 on frontline HIV counselling staff. However, the following section, based on a recent paper, examines the impact of the pandemic on the health workforce in India and argues that it is time for significant changes in the system. I co-authored this paper with Indian colleagues, titled COVID-19 and health workforce in India: Time for radical change in the book *Coronasphere* (Bisht et al., 2022).

One of the main challenges faced by the health workforce in India during the pandemic has been inadequate staffing levels. With the rapid increase in COVID cases, healthcare workers have been overburdened and have had to work under challenging conditions with limited support and resources. This has led to burnout, high-stress levels, and exhaustion among healthcare workers at the forefront of the pandemic response (Bisht et al., 2022).

The pandemic has also increased the workload for healthcare workers in India, who have had to respond to the increasing demand for healthcare services. This has further strained the already overburdened healthcare system and highlighted the need for a more resilient and robust health workforce. The authors argued that the government needs to invest in the health workforce, including providing training and support to ensure they have the necessary skills and knowledge to respond effectively to health crises (Bisht et al., 2022).

In addition to these challenges, research studies during the pandemic have revealed a lack of collaboration and coordination among staff from different levels of the health system hierarchy. The authors suggested that there is a need for a more integrated and collaborative approach to healthcare that allows better communication and coordination between different levels of the system, including the government, healthcare providers, and communities (Bisht et al., 2022).

In conclusion, the COVID-19 pandemic has exposed the weaknesses in India’s current health workforce system, and a radical change is needed to improve the capacity and resilience of the system (Khetrapal and Bhatia, 2020). Bisht et al. (2020) argued that the government needs to invest in the health workforce and the health system to ensure it is better equipped to respond to future health crises. By doing so, India will be better prepared to provide high-quality healthcare services to its citizens and respond effectively to future health crises.

8.8. Summarising Strength-Based Ideas from the AI Process

This chapter has highlighted the importance of soliciting feedback from HRGs and FCS to identify and address barriers to programme effectiveness in HIV counselling services. It found that organisational factors and a lack of social understanding are significant challenges that must be addressed to improve programme effectiveness. The recommendations provided by the CRs for programme design and implementation include client-centred counselling strategies, individualised counselling, developing linkages for HRGs, improving data sharing and reporting capabilities, and motivating staff. Additionally, privacy and confidentiality were identified as significant challenges faced by the CRs, indicating the need for a separate venue for counselling and testing services to protect the client’s identity and deliver private sessions in comfortable settings. Overall, this research emphasises the importance of stakeholder involvement in programme design and implementation to improve effectiveness and create a society that supports HRGs.

This project has identified that HRGs and FCS perceive organisational factors and lack of social understanding as critical barriers to programme effectiveness. The combined description by CRs expressed a counselling programme that adhered to programme guidelines, had a client-centred counselling strategy, had strategies around individualised counselling and developing linkages for HRGs, improved data sharing and reporting capabilities, had techniques to motivate staff, delivered wages on time, and had zero tolerance to discrimination to create a society that supports HRGs.

The CRs wanted the guidelines for district-level programme operations to be routinely updated based on the clients' changing requirements. They requested that staff be trained periodically about these changes and criticised the programme for not adhering to national guidelines. They wished for a tailored counselling programme to meet their needs, including mental health counselling, employment, housing, and behaviour change support. Although some suggestions seemed outside of the programme's scope, the programme could incorporate staff training and develop effective linkages with other agencies for delivering such complex services.

The CRs suggested that the programme needs to digitise HIV counselling and testing-related data. It should ensure that the data are always shared anonymously and securely stored. The programme must adopt accurate data collection and reporting techniques. It should also provide timely, regular increments and salary rewards to maintain designated roles for extended periods. Strategies were also recommended for better social support of HRGs and for creating a zero-tolerance policy against discrimination.

The above sections explored the perspectives of CRs, retracted from their drawings and FGDs related to their dreams of an effective HIV counselling programme and how they designed it for the Una district. The content depicts key moments of co-constructing dialogue for building the images of a shared future where they implement a practical design for the HIV counselling programme through various strategies, while discussing the challenges that must be addressed.

8.9. Recommendations for Policy and Practice

Based on the findings, the Indian government can take the following steps to improve the HIV counselling programme:

Advocate for improved tracking of HIV counselling outcomes: There is a lack of standardisation in reporting counselling outcomes for HRGs. This makes it challenging to measure the effectiveness of counselling programmes and accurately identify improvement areas. The government could lobby for improvements in this area by incorporating qualitative measures in reporting processes to collect data on counselling programmes' effectiveness.

Advocate for standardisation in reporting on HIV counselling programme in India for HRGs: The Joint United Nations Programme on HIV/AIDS (UNAIDS) provides valuable insights into the health and wellbeing of HRGs, but the reduced focus on counselling makes it challenging to track the progress of programme over time. It is recommended that the programme authorities adopt an improved reporting protocol to improve accountability that captures qualitative counselling measures such as behavioural change. This will provide a consistent and repeatable measurement of progress for addressing health outcomes of HRGs in India. To achieve this, HIV+/HRG data digitisation can be implemented, and identification checks to ensure transparency which can discourage any duplication of data or padding (Ramachandran, 2018). This will ensure higher accountability from the start and stop perfunctory implementation.

Specific performance indicators can be added to measure programme effectiveness at stages of implementation. Implementation level indicators can verify whether the activities were completed on time and within budget; the data were entered in real-time; were complete, accurate, and valid; data reporting followed standard operating procedures; and whether the overall process reduced errors improved efficiency and productivity, compared to the earlier system (Iyengar et al., 2018). These indicators can also measure counselling adherence—whether counselling leads to an HIV test, was it a complete counselling session, and how many new registrations and existing registrations undergo a complete counselling session. Daily logs, online visibility, and feedback mechanisms can be implemented to measure commitment. Real-time data analysis can also be used for continuous improvement and informed decision-making. Intangible benefits such as staff culture and higher retention can also be measured (Iyengar et al., 2018).

Revise content for HIV counselling programme in India for HIV-positive individuals: It is crucial for health and education professionals to have a comprehensive understanding of the rights of HRGs. To achieve understanding, the programme needs to educate health professionals and educators on the rights of HRGs, as outlined in the NACO (2020) guidelines. It needs to provide opportunities for HRGs to share their perspectives on healthcare with policymakers, health professionals, and teachers through partnerships with organisations such as the Indian Network for People Living with HIV/AIDS (INP+, 2022) and the National Association of People Living with HIV/AIDS (NAP+, 2020). Furthermore, it is required to foster ongoing collaboration and engagement with PLWHIV to ensure that their needs and rights are addressed through consultations with the National Positive People’s Network (NP+Net, 2021). The programme should enforce processes and procedures for accountability towards respecting the rights of HRGs. HRGs face numerous challenges, including stigma and discrimination, which negatively impact their health and well-being. The government must establish legal accountability for protecting the rights of HRGs, including their access to quality healthcare and counselling services.

Create spaces for HRGS to share their perspectives on health issues with stakeholders: Policymakers and health professionals involved in decision-making about the health of HRGs need to hear direction from HRGs' about their crucial health issues. By increasing HRGs' voices and minimising the role of intermediaries, such spaces can help change attitudes and promote active participation in decision-making related to the programme (NAP+, 2020; NP+Net, 2021). The involvement of organisations like NAP+ and NP+Net, that represent the rights and concerns of HRGs, can be instrumental in providing such opportunities. Health professionals must have a comprehensive understanding of the rights of HRGs. This can be achieved through incorporating the guidelines of NACO and the best practices of organisations such as INP+, NAP+, and NP+Net into the curricula of relevant professional bodies and requiring individuals seeking registration to demonstrate competence in applying these principles (INP+, 2022; NACO, 2020; NAP+, 2020; NP+Net, 2021).

Incorporate Indian systems of medicine into the Indian HIV counselling programme: The dominance of the allopathic treatment system in the Indian public health system has led to the neglect of other health paradigms, including the ISM. A locally strengthened public health system that considers social factors is crucial for a comprehensive public health response. AYUSH systems have a long history of use in India and offer a unique approach to health and wellness that can complement conventional Western medicine. Integrating AYUSH into the HIV programme can empower individuals to make informed decisions about their healthcare, increase access to care and support, and, ultimately, lead to better health outcomes.

Ensure financial stability and sustainability without relying on donor support: A fundamental way to reduce dependence on external funding is to increase domestic funding for the Indian HIV counselling programme. This can be done by incorporating the programme into the national health budget and by advocating for increased investment from the government and private sector. The government could diversify funding sources beyond government funding, including partnerships with the private sector, philanthropic organisations, and community-based organisations (Bautista-Arredondo, 2018). This can help reduce the risk of losing funding from any source. The programme can become more self-sustaining and less reliant on external funding by strengthening the health system as a whole and can further reduce the overall cost of the programme and increase the likelihood of sustained funding by promoting cost-effectiveness, use of local and innovative systems, and development of more efficient and effective delivery mechanisms.

Similar strategies have been successfully implemented in several countries and have been shown to increase the financial stability and sustainability of their HIV control programme (Dehne et al., 2017; Ford et al., 2018; Kim et al., 2013). By implementing these strategies, the Indian HIV counselling programme can become more self-sustaining and less reliant on external funding. The following section attempts to create a well-being model incorporating these strategies for a sustainable public health system.

8.10. Well-being Model for Indian HIV Counselling Programme

Public health research in India must appreciate social factors, as they would steer the direction towards local, technological, and innovative solutions to improve healthcare services (Nayak, Hazra and Sarkar, 2015; Raj et al., 2020; Sathya, 2018). This research indicates a growing need for increased transparency and accountability and a shared vision, particularly regarding allocating resources and implementing public health programmes.

A well-being model would have client-centredness at its core, tailoring the interventions based on the needs assessment of individual HRG (Jewkes, Murcott and

Godlonton, 2016). These interventions can be developed as tailored support plans addressing a range of needs, including healthcare, mental and physical health, financial stability, education and skill development, housing, legal assistance, career development, and spiritual support (Morris et al., 2017; WHO, 2020). This need-based approach would allow for the development of parallel pathways to enable ongoing support to HRGs.

The well-being model would incorporate a combination of top-down, bottom-up, and sideways approaches, wherever applicable (Murray et al., 2018). This generative model should involve funding from both government and private sectors (top-down) and individual and community needs assessment (bottom-up) with involvement from government, banks, rehabilitation centres, NGOs, hospitals, mental health organisations, and employers (sideways) (Singh, Khanna and Lal, 2018). The model should be holistic, moving from general to specific needs, and involve a sensitised community that works towards the betterment of these people. The model should also provide an accessible recruitment provision, small-scale business loans, sports associations, and publicly funded AYUSH treatment options for managing public health (Singh and Jyani, 2021). The model should emphasise increased spending on local resources, logistics and planning, and implementation (Hales et al., 2019).

The healthcare needs of HRGs are no different from those of the general population (Brooks et al., 2017), including basic physiological, safety, security, social, and esteem (Maslow, 1943). Their needs are natural and evolutionary, such as the need for technology that can help improve their health outcomes and increase engagement in care (Kuhnsv et al., 2020). The definition of health for HRGs is no different from that of any other individual, which includes physical, mental, and social wellbeing; and applies equally to all individuals, regardless of sexual orientation or gender identity (WHO, 1946). However, the social conditions in which HRGs are born, grow, live, work, and age, disproportionately affect their health (Marmot, 2005).

The main challenge is to ensure that this population has equitable access to healthcare services and to address the social determinants of health that affect their health outcomes. Being disadvantaged, the needs of HRGs can be diverse, including healthcare, mental and physical health, financial support, housing, legal aid, career guidance, rehabilitation, and spiritual support. Therefore, conducting a general to specific needs assessment is necessary to identify the areas where the HRGs require support (Scheibe, Drame, and Shannon, 2012). Based on the assessment, individualised support plans can be developed to address the specific needs of each HRG.

India has made progress towards protecting the rights of individuals, including those at risk of HIV, through several legal provisions that discourage discriminatory practices and criminal offences related to defamation. However, discrimination against at-risk populations remains a pervasive issue, and additional legal action is needed to address it. The criminalisation of prostitution in Indian law reinforces the stigmatisation of sex workers and contributes to their marginalisation and increased risk of HIV transmission. India’s shift in policy towards decriminalising sex work or providing support and legal protections for sex workers would go a long way in addressing this issue. Moreover, increasing awareness of human rights and legal implications can be accomplished through targeted education campaigns and by providing legal resources to HRGs.

In summary, a well-being model would be centred around locally available healthcare, mental health, legal, financial support, local housing, employment agencies, and NGOs to cater to the community’s specific needs. Additionally, real-time data analysis, staff culture, and higher retention can be used to measure intangible benefits. These provisions would improve the lives of people at risk of HIV, with accountability and transparency in reporting, specific performance, and success indicators.

8.11. Conclusion

The findings from this study provide valuable insights into ways to improve the HIV counselling programme. The summaries in this chapter have shown that the current programme faces several challenges, has limited resources, and lacks standardisation in counselling approaches. They further highlight the need to understand the barriers and facilitators for an effective HIV counselling programme. The recommendations offered in this study provide a roadmap for improving the programme. These recommendations focus on improving programme effectiveness, increasing resources, and standardising counselling approaches. By implementing these recommendations, the HIV counselling programme can become more effective and better equipped to meet the needs of HRGs. Moving forward, it will be essential to continue monitoring and evaluating the programme to ensure that it meets the needs of those it serves and identify improvement areas. The chapter also suggests a well-being model to achieve a highly effective HIV counselling programme that has the potential to manage many challenges discussed in this thesis.

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APPENDICES

<u>Appendix 1:</u> AUTEC Ethics Approval Letter

AUTEC Secretariat

Auckland University of Technology
D-88, WU406 Level 4 WU Building City Campus
T: +64 9 921 9999 ext. 8316
E: ethics@aut.ac.nz
www.aut.ac.nz/researchethics

16 November 2015

Cath Conn
Faculty of Health and Environmental Sciences

Dear Cath

Re Ethics Application: **15/387 How can the HIV counselling service in India be made more effective? An appreciative inquiry by counsellors and clients.**

Thank you for providing evidence as requested, which satisfies the points raised by the Auckland University of Technology Ethics Committee (AUTEC).

Your ethics application has been approved for three years until 16 November 2018.

As part of the ethics approval process, you are required to submit the following to AUTEC:

- A brief annual progress report using form EA2, which is available online through http://www.aut.ac.nz/researchethics. When necessary this form may also be used to request an extension of the approval at least one month prior to its expiry on 16 November 2018;
- A brief report on the status of the project using form EA3, which is available online through http://www.aut.ac.nz/researchethics. This report is to be submitted either when the approval expires on 16 November 2018 or on completion of the project.

It is a condition of approval that AUTEC is notified of any adverse events or if the research does not commence. AUTEC approval needs to be sought for any alteration to the research, including any alteration of or addition to any documents that are provided to participants. You are responsible for ensuring that research undertaken under this approval occurs within the parameters outlined in the approved application.

AUTEC grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to obtain this. If your research is undertaken within a jurisdiction outside New Zealand, you will need to make the arrangements necessary to meet the legal and ethical requirements that apply there.

To enable us to provide you with efficient service, please use the application number and study title in all correspondence with us. If you have any enquiries about this application, or anything else, please do contact us at ethics@aut.ac.nz.

All the very best with your research,

Kate O'Connor
Executive Secretary
Auckland University of Technology Ethics Committee

Cc: Balakrishnan Nair bnair@aut.ac.nz, Kate Diesfeld

Appendix 2: Client Advertisement

Dear Sir/Madam,

I would like to invite you to take part in a focus group (small discussion group) on (date-------------) about HIV counselling in district Una. It is about hearing your voice and giving you a place to make your views heard to help future counselling services. Your participation will be voluntary and you may withdraw at any time prior to the completion of data collection.

There would be four hours of discussion with breaks after every hour. More background information will be sent to those confirming attendance before the focus group. This could be sent by post or e-mail or by hand depending on which method will be convenient for you.

Your views are important and will be used to help strengthen HIV counselling service in district Una. I will share with you the findings of the research. You will receive support for your transport and food when you come for the focus group discussion. Also, there would be a token gift to participate in the discussions for devoting your time. The focus group discussions will be audio-taped.

If you would like to take part in the focus group on (date-----------) please let me know by contacting me directly or e-mail me or text me, WhatsApp or Viber me. I will be happy to call you back or text you as soon as I hear from you. You also have an option to contact your nearest HIV counselling centre and give your contact number to the counsellor. I will contact you from there. You will be called to discuss the research objectives and the group discussion venue. In addition, you will be contacted to discuss the schedule for focus group discussion and asked to give consent within one week.

You could also use a reply tear-off slip with my telephone at the bottom of this page.

Yours faithfully

TEAR OFF SLIP WITH MY NUMBER – PARTICIPANT CAN TEAR OFF SLIPS

Approved by the Auckland University of Technology Ethics Committee on **November 29, 2012** ***AUTEC Reference number*** **15/387**

Note: The Participant should retain a copy of this form.

Appendix 3: Consent Form for Focus Group Discussions

Project title: How can the HIV counselling service in India be made more effective?

Project Supervisor: Dr. Cath Conn (primary supervisor) and Professor Kate Diesfeld (secondary supervisor)

Researcher: Balakrishnan Nair

○ I have read and understood the information provided about this research project in the Information Sheet dated ……..

○ I have had an opportunity to ask questions and to have them answered.

○ I understand that identity of my fellow participants and our discussions in the focus group is confidential to the group and I agree to keep this information confidential.

○ I understand that notes will be taken during the focus group and that it will also be audio-taped and transcribed.

○ I understand that I may withdraw myself or any information that I have provided for this project at any time prior to completion of data collection, without being disadvantaged in any way.

○ If I withdraw, I understand that while it may not be possible to destroy all records of the focus group discussion of which I was part, the relevant information about myself including tapes and transcripts, or parts thereof, will not be used.

○ I agree to take part in this research.

○ I understand other participants might have a different sexuality than my own and will respect their sexuality.

○ I will keep private information that is shared during the focus group.

○ I will keep the personal information of my fellow participants confidential.

○ I wish to receive a copy of the report from the research (please tick one): Yes○ No○

Participant's signature: ………………………………………………………………………………………………

Participant's name: ………………………………………………………………………………………………

Participant's Contact Details: ……………………………………………………………………………….

Date:

Approved by the Auckland University of Technology Ethics Committee on **November 29, 2012** ***AUTEC Reference number*** **15/387**

Note: The Participant should retain a copy of this form.

Appendix 4: HIV Counsellor Information Sheet

Date Information Sheet Produced ………………..

Project Title: How can the HIV counselling service in India be made more effective?

An Invitation

My name is Balakrishnan, (you can call me Bala if you prefer) and I am a PhD student in the Department of Public Health, Auckland University of Technology, Auckland, New Zealand. I am conducting this research to find out how the HIV counsellors' perspectives can improve the overall HIV counselling services in India.

I am here to invite you to share your views and your experiences on how the HIV counselling services delivered under the Indian National AIDS Control Programme can be improved. This research explores that idea in relation to HIV counselling in district Una. The focus group discussion will explore your experiences of the existing HIV counselling service in district Una and your viewpoints on the strategies to improve it. It is about hearing your voice and giving you a place to make your views heard to help future services. Your participation will be voluntary and you may withdraw at any time prior to the completion of data collection.

I will be seeking the help of four HIV counsellors like you to volunteer to participate in a focus group. The focus group will be audio-taped. Also, all information that you give to me will be confidential and used only for the purpose of this study. Before we start, I will give you the information sheet and consent form to read and sign if you agree. However, if at any point you feel uncomfortable to talk or answer any questions, please feel free tell me or you may also choose not to answer.

What is the purpose of this research?

How can the HIV counselling service in India be made more effective?

How were you identified and why are you invited to participate in this research?

You have been identified on the basis of the contact made on seeing my research advertisement at your local HIV counselling centre or through your local NGO. Thank you for showing interest to participate in my research and hereby you are getting more information about my study.

What will happen in this research?

I will meet with you to introduce myself and answer any questions you may have about my study; I will also walk you through the forms (information sheet, confidentiality and consent forms). If you decide to take part in this research, I will pass on a consent form for you to read. When you have completed the form, sign it and please send it to me via email in my advertisement. I will then invite you with details of the venue and time for the focus group discussion.
You will be expected to give approximately four hours of your time.
We will have one focus group discussion with break after every hour, which I, Balakrishnan, will run.
I will also be inviting participants from the following sources as part of my data collection:

- HIV counselling centre Bangana locality
- HIV counselling centre Daulatpur locality
- HIV counselling centre Una central
- Mobile HIV counselling centre (on wheels)
- SAHYOG - NGO, District Una, Himachal Pradesh, India
- HIRD – NGO, District Una, Himachal Pradesh, India
- Himachal Laghu Udyog Kalyan Sangh – NGO, District Una, Himachal Pradesh, India

The focus group discussion will be a friendly discussion on what you think about current HIV counselling services in your communities; what is good about current HIV counselling services? What would you change? How?

I will help you if you need anything to be translated as I speak fluent Hindi and Punjabi and other local dialects.

You will also be invited to discuss a summary of findings. I will pay for your transport and food when you come for the focus group discussion. Also, there would be a token gift to participate in the discussions for devoting your time.

What are the discomforts and risks?

It is possible that you or your fellow members in the discussion may experience distress when talking about issues of their HIV counselling experiences and the stigma and discrimination associated with it, or may feel uncomfortable when talking about the sexual practice advice given during HIV counselling, in front of their peers. To mitigate this risk, I will look out for signs of emotional risks, discomfort or embarrassment. If you experience discomfort or embarrassment, I will immediately consult with confidential counselling service regarding how best to support you. You will be provided details of the free counselling service provided by the participating NGOs: SAHYOG Office (+91-1783-237495); HIRD Office (+91-1782-234902) and of their right to leave the interview discussion at any point. Furthermore, you can choose not to answer certain questions; ask the audio recording to be turned off; or leave the group session without giving a reason.

How will these discomforts and risks be alleviated?

I will look out for any signs of discomfort or embarrassment. If you experience discomfort or embarrassment, I will immediately consult with confidential counselling service regarding to support you best. You will be provided details of the free counselling service provided by the participating NGOs: SAHYOG, HIRD. This might help to alleviate your discomfort.

What are the benefits?

By taking part in this study you may experience the individual benefit of sharing your views and getting your voice heard on HIV counselling in your community. It is anticipated that taking part in this study will help strengthen HIV counselling in India. Your involvement will assist me to attain a PhD degree in Public Health. The research findings will be presented in future academic publications and presentations.

How will my privacy be protected?

Protecting your privacy is very important to the study. You will be asked to create a false name to be used in discussion records and when quoting any information from the study in the thesis, journal articles or conference presentations. The researcher will also maintain your privacy by changing any identifying details in the records/transcripts and resulting research publications.

What are the costs of participating in this research?

You will receive reimbursement of all reasonable travel costs using public transport to travel to the study venue. You will also be provided with refreshments and snacks at the end of each focus group discussion. Also, there would be a token gift to participate in the discussions for devoting your time in the discussions.

What opportunity do I have to consider this invitation?

You have up to one week to consider taking part in the study. You can get in touch with me to ask any questions or get me to explain any issues of concern. If I do not hear from you within this time, I will contact you to ask if you would still like to be part of the research.

How do I agree to participate in this research?

If you decide to take part in the research, you will need to complete and sign the consent form. You will then give this form to me via email or the post. An invitation letter will then be sent to you, with the venue, date and times for focus group discussion. However, if you prefer to have the discussion in an alternative venue, this can be discussed with the other members of the group.

Will I receive feedback on the results of this research?

I will be contacting you to give feedback and share the summary of my research findings. The feedback and summary of research findings will be shared via phone if you want to do so. You may be asked during the focus group discussion to provide suggestions on categorising and coding. The summary finding will be sent to all the counselling centres and NGOs later and will be displayed on the notice board for you to view.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Primary Supervisor, Dr. Cath Conn, cath.conn@aut.ac.nz, 0064 9 921 9999 ext. 7407 (this is a New Zealand number which might be costly from India, so you may prefer to email instead). Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEC, Kate O’Connor, ethics@aut.ac.nz, 921 9999 ext. 6038.

Whom do I contact for further information about this research?

Researcher Contact Details: Balakrishnan Nair, bshnair@yahoo.com

Project Supervisor Contact Details: Project Primary Supervisor, Dr. Cath Conn, cath.conn@aut.ac.nz, 0064 9 921 9999 ext 7407 (this is a New Zealand number which might be costly from India, so you may prefer to email instead).

***Approved by the Auckland University of Technology Ethics Committee on* November 29, 2012 *AUTEC Reference number* 15/387**

Note: The Participant should retain a copy of this form.

Appendix 5: Client information Sheet

Date Information Sheet Produced ……………….

Project Title: How can the HIV counselling service in India be made more effective?

An Invitation

My name is Balakrishnan, (you can call me Bala if you prefer) and I am a PhD student in the Department of Public Health, Auckland University of Technology, Auckland, New Zealand. I am conducting this research to find out how the HIV counsellors perspectives can improve the overall HIV counselling services in India.

I am here to invite you to share your views and your experiences on how the HIV counselling services delivered under the Indian National AIDS Control Programme can be improved. This research aims to get the clear point of view of the clients in relation to HIV counselling in District Una. The focus group discussion will explore your experiences of the existing HIV counselling service in District Una and your viewpoints on the strategies to improve it. It is about hearing your voice and giving you a place to make your views heard to help future services. Your participation will be voluntary and you may withdraw at any time prior to the completion of data collection.

I will be seeking the help of four clients like you, who have received HIV counselling sessions from the HIV counselling centres of district Una, to participate in a focus group. The focus group will be audio-taped. Also, all information that you give to me will be confidential and used only for the purpose of this study. Before we start, I will give you the information sheet and consent form to read and sign if you agree. However, if at any point you feel uncomfortable to talk or answer any questions, please feel free tell me or you may also choose not to answer.

What is the purpose of this research?

How can the HIV counselling service in India be made more effective?

How were you identified and why are you invited to participate in this research?

You have been identified in response to your call, text, email or message that you have left with the HIV counsellor in response to an advertisement that was placed in your local HIV counselling centre or at your local NGO. Thank you for showing interest to participate in my research. Hereby you are getting more information about my study. Participating clients will be over 18 years old and have received HIV counselling session from the HIV counselling centres in District Una. Clients under 18 years of age will not be included.

What will happen in this research?

I will meet with you to introduce myself and answer any questions you may have about my study;
I will also walk you through the forms (information sheet, confidentiality and consent forms). If you decide to take part in this research, I will pass on a consent form for you to read. When you have completed the form, please sign it and send it to me via email in my advertisement.
I will then invite you with details of the venue and time for the focus group discussion.
You will be expected to give approximately four hours of your time.
We will have one focus group discussion with break after every hour, which I, Balakrishnan, will run.
I will also be inviting clients from from the following sources as part of my data collection:

- HIV counselling centre Bangana locality
- HIV counselling centre Daulatpur locality

- HIV counselling centre Una central
- Mobile HIV counselling centre (on wheels)
- SAHYOG - NGO, District Una, Himachal Pradesh, India
- HIRD – NGO District Una, Himachal Pradesh, India
- Himachal Laghu Udyog Kalyan Sangh – NGO, District Una, Himachal Pradesh, India

The focus group discussion will be a friendly discussion on what you think about current HIV counselling services in your communities; what is good about current HIV counselling services? What would you change? How?

I will help you if you need anything to be translated as I speak fluent Hindi and Punjabi and other local dialects.

I will pay for your transport and food when you come for the focus group discussion. Also, there would be a token gift to participate in the discussions for devoting your time.

What are the discomforts and risks?

It is possible that you or your fellow participants may experience distress when talking about issues of their HIV counselling experiences and the stigma and discrimination associated with it, or may feel uncomfortable when talking about the sexual practice advice given during HIV counselling, in front of their peers. To mitigate this risk, I will look out for signs of emotional risks, discomfort or embarrassment. If you experience discomfort or embarrassment, I will immediately consult with confidential counselling service regarding how best to support you. You will be provided details of the free counselling service provided by the participating NGOs: SAHYOG Office (+91-1783-237495); HIRD Office (+91-1782-234902) and of their right to leave the interview discussion at any point. Furthermore, you can choose not to answer certain questions; ask the audio recording to be turned off; or leave the group session without giving a reason.

How will these discomforts and risks be alleviated?

I will look out for any signs of discomfort or embarrassment. If you or your fellow members experience discomfort or embarrassment, I will immediately consult with confidential counselling service regarding how best to support you. You will be provided details of the free counselling service provided by the participating NGOs: SAHYOG, HIRD. This might help to alleviate your discomfort.

What are the benefits?

By taking part in this study you may experience the individual benefit of sharing your views and getting your voice heard on HIV counselling in your community. It is anticipated that taking part in this study will help strengthen HIV counselling in India. Your involvement will assist me to attain a PhD degree in Public Health. The research findings will be presented in future academic publications and presentations.

How will my privacy be protected?

Protecting your privacy is very important to my study. You will be asked to create a false name to be used in the discussions and when quoting any information from the study in my thesis, journal articles or conference presentations. The researcher will also maintain your privacy by changing any identifying details in the records/transcripts and resulting research publications.

What are the costs of participating in this research?

You will receive reimbursement of all reasonable travel costs using public transport to travel to the study venue. You will also be provided with refreshments and snacks at the end of each focus group discussion. Also, there would be a gift to participate in the discussions for devoting your time in the discussions.

What opportunity do I have to consider this invitation?

You have up to one week to consider taking part in the study. You can get in touch with me to ask any questions or get me to explain any issues of concern. If I do not hear from you within this time, I will contact you to ask if you would still like to be part of the research.

How do I agree to participate in this research?

If you decide to take part in the research, you will need to complete and sign the consent form. You will then give this form to me via email or the post. An invitation letter will then be sent to you, with the venue, date and times for focus group discussion. However, if you prefer to have the discussion in an alternative venue, this can be discussed with the other members of the group.

Will I receive feedback on the results of this research?

I will be contacting you to give feedback and share the summary of my research findings. The feedback and summary of research findings will be shared via phone if you want to do so. You may be asked during the focus group discussion to provide suggestions on categorising and coding. The summary finding will be sent to all the counselling centres and NGOs later and will be displayed on the notice board for you to view.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Primary Supervisor, Dr. Cath Conn, cath.conn@aut.ac.nz, 0064 9 921 9999 ext. 7407 (this is a New Zealand number which might be costly from India, so you may prefer to email instead). Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEC, Kate O'Connor, ethics@aut.ac.nz, 921 9999 ext. 6038.

Whom do I contact for further information about this research?

Researcher Contact Details: Balakrishnan Nair, Email: bshnair@yahoo.com; 0091-98151-53838

Project Supervisor Contact Details: Project Primary Supervisor, Dr. Cath Conn, cath.conn@aut.ac.nz, 0064 9 921 9999 ext 7407 (this is a New Zealand number which might be costly from India, so you may prefer to email instead).

***Approved by the Auckland University of Technology Ethics Committee on* November 29, 2012 *AUTEC Reference number* 15/387**

Note: The Participant should retain a copy of this form.

Appendix 6: Confidentiality Agreement for Data transcription

Project title: How can the HIV counselling service in India be made more effective?

Project Supervisor: Dr. Cath Conn (primary supervisor) and Professor Kate Diesfeld (secondary supervisor)
Researcher: Balakrishnan Nair

- ○ I understand that all the material I will transcribe is confidential.
- ○ I understand that the contents of the recordings can only be discussed with my supervisors and field supervisor.
- ○ I will not keep any copies of the transcripts nor allow third parties access to them.

Transcriber's signature: ……………………………………………………………………………………………

Transcriber's name: ……………………………………………………………………………………………

Transcriber's Contact Details (if appropriate):

……………………………………………………………………………………….

……………………………………………………………………………………….

……………………………………………………………………………………….

Date:

Project Supervisor's Contact Details:
Dr. Cath Conn
AUT University, North Shore Campus, 90 Akoranga Drive
Northcote, Auckland 0627, New Zealand
Telephone: 0064 9 921 9999 Ext 7407
Email: cath.conn@aut.ac.nz

Approved by the Auckland University of Technology Ethics Committee on November 29, 2012 *AUTEC Reference number* 15/387

Note: The Transcriber should retain a copy of this form.

Appendix 7: Confidentiality Agreement for Data interpretation

Project title: How can the HIV counselling service in India be made more effective?

Project Supervisor: Dr. Cath Conn (primary supervisor) and Professor Kate Diesfeld (secondary supervisor)
Researcher: Balakrishnan Nair

○ I understand that the focus group discussion material or the content I translate are confidential.

○ I understand that the content of the recordings can only be discussed with supervisors and field supervisor.

○ I will not keep any copies of the translations nor allow third parties access to them.

Interpreter's signature: ....

Interpreter's name: ....

Interpreter's Contact Details:

……………………………………………………………………………………….

……………………………………………………………………………………….

……………………………………………………………………………………….

Date:

Project Supervisor's Contact Details:
Dr. Cath Conn
AUT University, North Shore Campus, 90 Akoranga Drive
Northcote, Auckland 0627, New Zealand
Telephone: 0064 9 921 9999 Ext 7407
Email: cath.conn@aut.ac.nz

Approved by the Auckland University of Technology Ethics Committee on **November 29, 2012** ***AUTEC Reference number*** **15/387**

Note: The Translator should retain a copy of this form.

<u>Appendix 8:</u> Researcher safety protocol

Project title: How can the HIV counselling service in India be made more effective?

Project Supervisor: Dr. Cath Conn (primary supervisor) and Professor Kate Diesfeld (secondary supervisor)
Researcher: Balakrishnan Nair

- ○ <u>Location</u>: HIV counsellors and clients will have their respective focus groups held at the Una community centre or the local authority offices.

- ○ <u>Post-activity action</u>: Balakrishnan will maintain communication through text and email with the supervisors and field supervisor. He will make them aware of the focus group schedule, venue and completion times. Balakrishnan will contact the supervisors and field supervisor via phone or text or email within an hour of the completion of a focus group. If by any chance, Balakrishnan is unable to contact his supervisors and field supervisor within the said time, they can try to contact him via phone, text or email. If his phone is not reachable, the supervisor can contact his family or field supervisor can contact Balakrishnan's family and ask them to do necessary action.

- ○ <u>Country exit strategy for Balakrishnan Nair</u>: Balakrishnan will register himself with the local Police Station in case of any emergency. Balakrishnan will notify his field supervisor, liaisons and his family about his stay in Una. Balakrishnan was born and brought up in North India, so has contacts with the local policing. The Indian police stations do have investigation and crisis management protocols for researchers from overseas. Balakrishnan's extended family lives in Chandigarh which is approximately 90 kms from Una. His liaisons in Una are locally available within 15 minutes reach. Balakrishnan will keep his passport and emergency cash at hand in the event that emergency travel via road is necessary. A visa is not required for Balakrishnan as he is an Indian citizen. Balakrishnan will text or email supervisors at the earliest available opportunity and provide an update if there is an emergency situation.

- ○ <u>Communication with supervisors</u>: Balakrishnan will make fortnightly contact with supervisors via email and a monthly Skype or telephone call. Supervisors will contact members of Balakrishnan's family in India if they do not hear from him for over two weeks. If neither party is able to contact Balakrishnan, then his liaisons in Una and his field supervisor will be notified to take necessary action.

Approved by the Auckland University of Technology Ethics Committee on **<u>November 29, 2012</u>** *AUTEC Reference number* **<u>15/387</u>**

Appendix 9: Focus Group Discussion (Indicative Questions)

The Appreciative Inquiry has a 4-D process. The focus group discussion will have the same outline for both the groups. Following are the questions that will be asked during the focus group discussion.

Discovery: What was the best HIV counselling service experience you ever had?

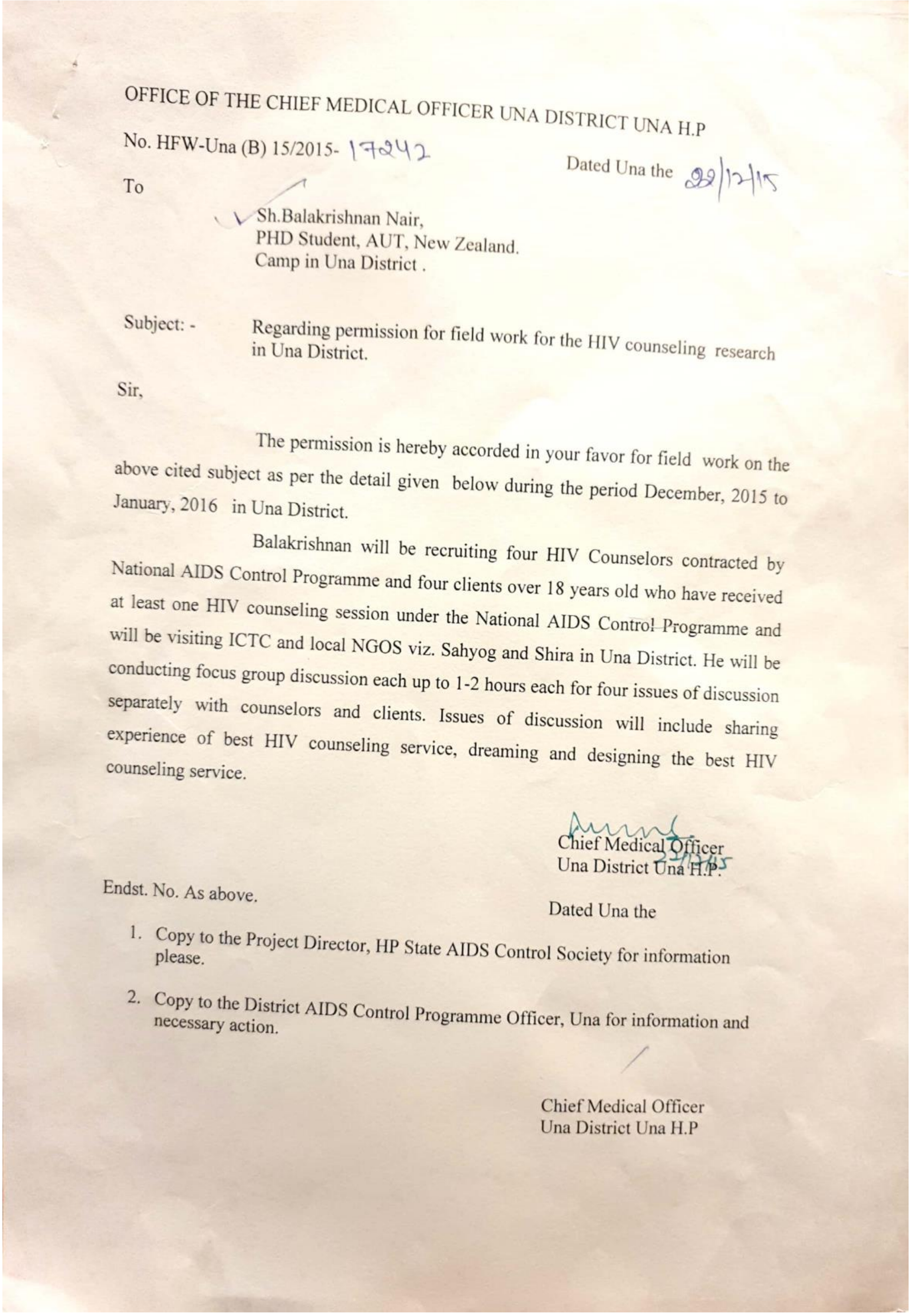
Dream: How do you envision the best HIV counselling service?

Design: How do you think such an HIV counselling service can be designed?

Destiny: How do you visualise achieving your design in the actual settings?

Approved by the Auckland University of Technology Ethics Committee on **November 29, 2012** ***AUTEC Reference number*** **15/387**

<u>Appendix 10:</u> Locality Approval Letter from the District Una Chief Medical Officer's Officer



OFFICE OF THE CHIEF MEDICAL OFFICER UNA DISTRICT UNA H.P

No. HFW-Una (B) 15/2015- 17242

Dated Una the 22/12/15

To

Sh.Balakrishnan Nair,
PHD Student, AUT, New Zealand.
Camp in Una District .

Subject: - Regarding permission for field work for the HIV counseling research in Una District.

Sir,

The permission is hereby accorded in your favor for field work on the above cited subject as per the detail given below during the period December, 2015 to January, 2016 in Una District.

Balakrishnan will be recruiting four HIV Counselors contracted by National AIDS Control Programme and four clients over 18 years old who have received at least one HIV counseling session under the National AIDS Control Programme and will be visiting ICTC and local NGOS viz. Sahyog and Shira in Una District. He will be conducting focus group discussion each up to 1-2 hours each for four issues of discussion separately with counselors and clients. Issues of discussion will include sharing experience of best HIV counseling service, dreaming and designing the best HIV counseling service.

Chief Medical Officer
Una District Una H.P.

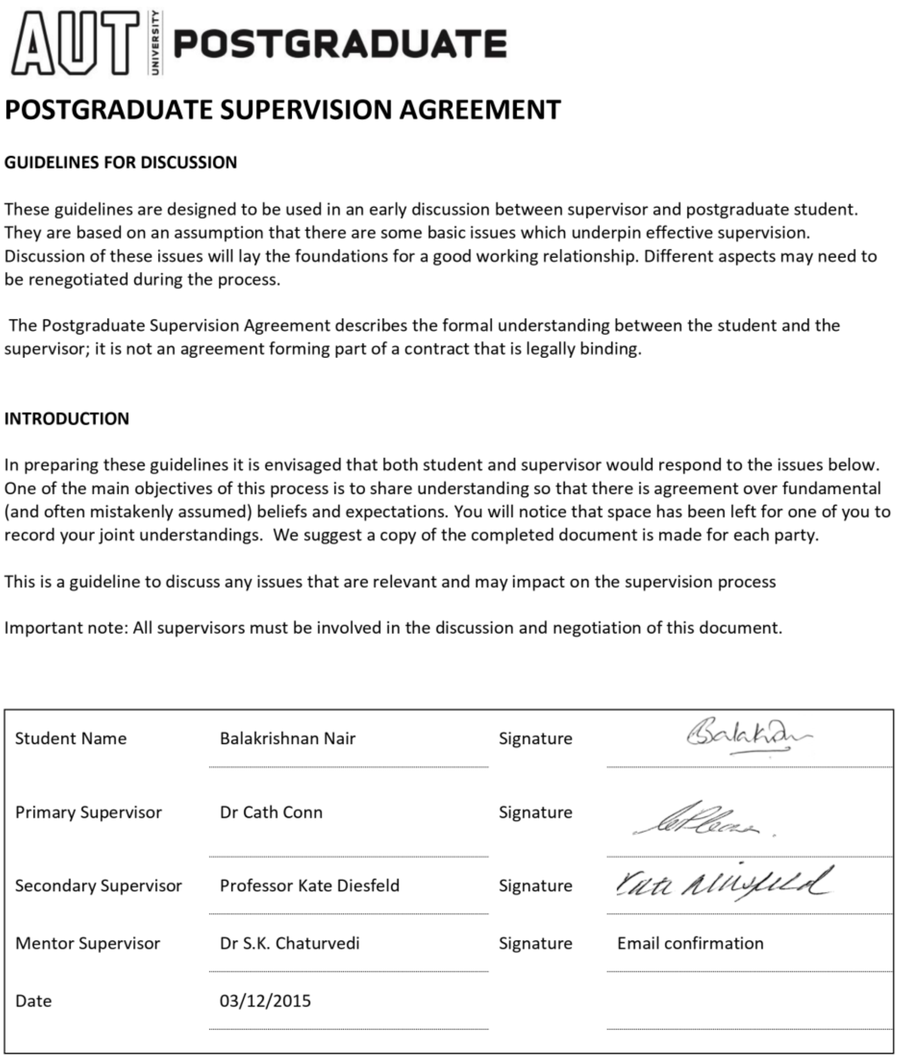
Endst. No. As above.

Dated Una the

1. Copy to the Project Director, HP State AIDS Control Society for information please.
2. Copy to the District AIDS Control Programme Officer, Una for information and necessary action.

Chief Medical Officer
Una District Una H.P

Appendix 10: Postgraduate Supervision Agreement



AUT UNIVERSITY POSTGRADUATE

POSTGRADUATE SUPERVISION AGREEMENT

GUIDELINES FOR DISCUSSION

These guidelines are designed to be used in an early discussion between supervisor and postgraduate student. They are based on an assumption that there are some basic issues which underpin effective supervision. Discussion of these issues will lay the foundations for a good working relationship. Different aspects may need to be renegotiated during the process.

The Postgraduate Supervision Agreement describes the formal understanding between the student and the supervisor; it is not an agreement forming part of a contract that is legally binding.

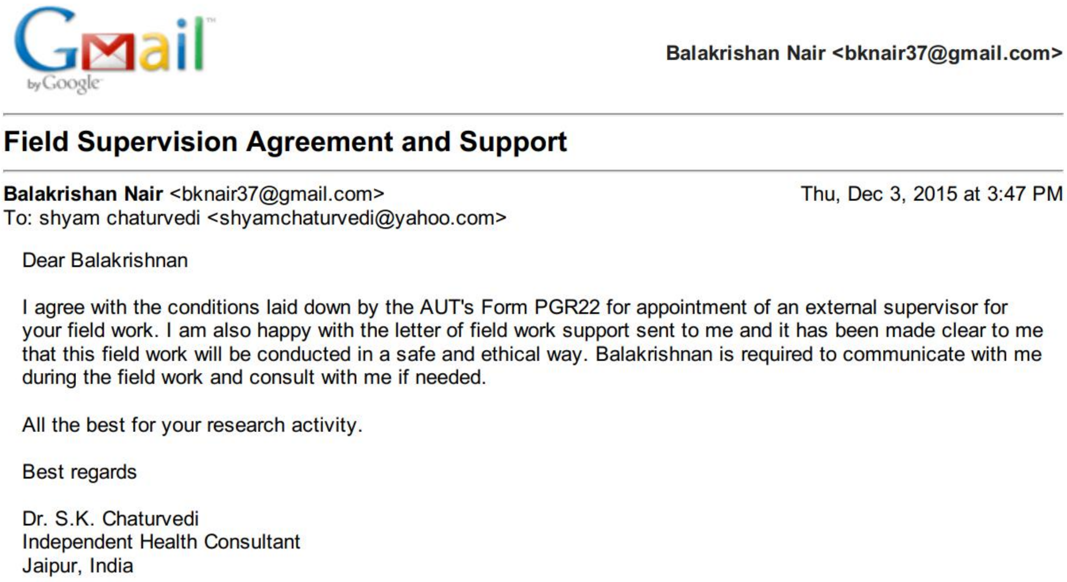
INTRODUCTION

In preparing these guidelines it is envisaged that both student and supervisor would respond to the issues below. One of the main objectives of this process is to share understanding so that there is agreement over fundamental (and often mistakenly assumed) beliefs and expectations. You will notice that space has been left for one of you to record your joint understandings. We suggest a copy of the completed document is made for each party.

This is a guideline to discuss any issues that are relevant and may impact on the supervision process

Important note: All supervisors must be involved in the discussion and negotiation of this document.

Student Name	Balakrishnan Nair	Signature	
Primary Supervisor	Dr Cath Conn	Signature	
Secondary Supervisor	Professor Kate Diesfeld	Signature	Kate Diesfeld
Mentor Supervisor	Dr S.K. Chaturvedi	Signature	Email confirmation
Date	03/12/2015		



Gmail by Google

Balakrishan Nair <bknair37@gmail.com>

Field Supervision Agreement and Support

Balakrishan Nair <bknair37@gmail.com>
Thu, Dec 3, 2015 at 3:47 PM
To: shyam chaturvedi <shyamchaturvedi@yahoo.com>

Dear Balakrishnan

I agree with the conditions laid down by the AUT's Form PGR22 for appointment of an external supervisor for your field work. I am also happy with the letter of field work support sent to me and it has been made clear to me that this field work will be conducted in a safe and ethical way. Balakrishnan is required to communicate with me during the field work and consult with me if needed.

All the best for your research activity.

Best regards

Dr. S.K. Chaturvedi
Independent Health Consultant
Jaipur, India