A Study to Determine the Factors Affecting Treatment Adherence for Hypertension and Diabetes in Different Contexts

Final Report- Revised

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Contents

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(Public Health Resource Society)

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List of abbreviations

AB	Ayushman Bharat
ANM	Auxiliary Nurse Midwife
ASHA	Accredited Social Health Activist
AWC	Anganwadi Centre
AYUSH	Ayurveda, Yoga, and Naturopathy, Unani, Siddha and Homoeopathy
BCC	Behaviour Change Communication
BP	Blood Pressure
CBAC	Community-Based Assessment Checklist
CG	Chhattisgarh
CHO	Community Health Officer
CHW	Community Health Worker
DGD	Delhi Government Dispensary
DH	District Hospital
DM	Diabetes Mellitus
EDL	Essential Drug List
FGD	Focus Group Discussion
GD	Gestational Diabetes
HBA1C	Hemoglobin A1C
HWC	Health and Wellness Centre
HT	Hypertension
IEC	Information, Education, Communication
ICMR-INDIAB	Indian Council of Medical Research- INdia DIABetes
JH	Jharkhand
KFT	Kidney Function Test
KII	Key Informant Interview
LFT	Liver Function Test
LNJP hospital	Lok Nayak Hospital/Irwin Hospital
LMIC	Low and Middle Income Country
MCQ	Multiple Choice Question
MO	Medical Officer
MoHFW	Ministry of Health and Family Welfare
MPW	Multi-Purpose Worker
NCD	Non-Communicable Disease
NCT- Delhi	National Capital Territory- Delhi

NFHS	National Family Health Survey
NHM	National Health Mission
NHSRC	National Health Systems Resource Centre
NPCDCS	National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases and Stroke
IDF	International Diabetes Federation
OBC	Other Backward Class
OOPE	Out Of Pocket Expenditure
PHC	Primary Health Centre
PHRS	Public Health Resource Society
PHRN	Public Health Resource Network
PVTG	Particularly Vulnerable Tribal Group
PLA	Participatory Learning and Action
RMP	Registered Medical Practitioner
SC	Schedule Caste
STP	Standard Treatment Protocol
SHGs	Self Help Groups
TA	Treatment Adherence
TPB	Theory of Planned Behaviour
UPHC	Urban Primary Health Centre
WHO	World Health Organization

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Executive Summary

Non communicable diseases (NCDs) are considered to be silent epidemic, posing a threat to public health in terms of morbidity and mortality, as well as adding to the economic burden. They are not just a major burden on the public health systems, but also contribute to financial hardship at households and individual levels. As per the World Health Organization (WHO), NCDs accounts for almost 71% of the total global deaths and kills about 41 million people globally each year. About 82% of all premature NCD deaths occur within low- and middle-income countries (LMICs). The total NCD mortality burden on LMICs is around 77% [31]. In India, about 5.87 million people die each year from NCDs, accounting for 60% of the total deaths. Evidence shows that the risk of an Indian for a premature death between 30 and 70 years of age from any one of the four major NCDs, namely cancer, diabetes, cardio-vascular diseases and stroke, was about 23% in 2016 [59]. India is struggling to tackle the rising burden of NCDs due to epidemiological and demographic transitions.

India has made huge strides in responding to NCDs. However, the high burden of NCDs demonstrates challenges in the implementation of national guidelines at the ground level. An attempt is being made to establish equitable and affordable primary care prevention, treatment, and support systems for NCDs at the primary and community levels including elements of Health and Wellness Centres (HWCs)[1], Primary Health Centres (PHCs), Accredited Social Health Activists (ASHAs) Auxiliary Nurse Midwives (ANMs). However, identifying gaps and solutions at different levels of implementation is important for developing a sustainable effective NCD care delivery.

With this background and in response to an invitation from the National Health Systems Resource Centre, a multi-centric mixed-method study has been conducted to assess the proportion of treatment adherence (TA) and identify its major socio-economic, health systems, condition-related, therapy-related, and patient-related factors among people living with diabetes and hypertension in different contexts. The study has been conducted to help in planning targeted interventions to address the issue of poor treatment adherence with contextual specificity. The contexts comprise tribal, non-tribal rural and urban locations.

Methods: The study utilised mixed methods, including qualitative and quantitative components, of observation, Focussed Group Discussion (FGDs), Case studies and Key Informant interviews (KII).

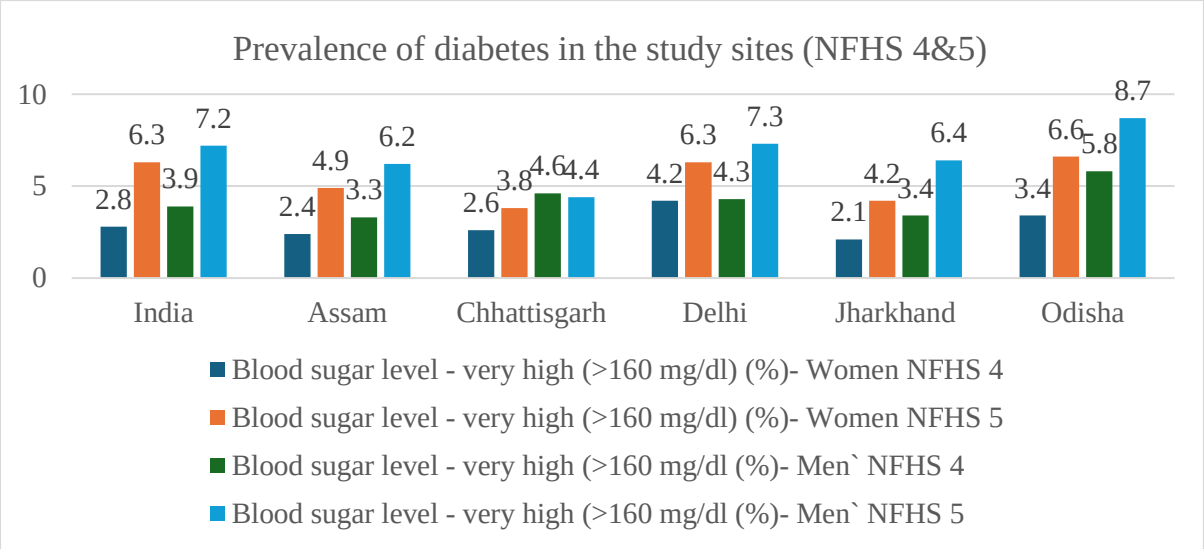
Study location: The research study was conducted in Delhi (Tier-1 city, urban slum), Puri district in Odisha (Tier- 2 city), Assam (Rural and tribal), Jharkhand (Tribal rural area), and Chhattisgarh (Non-tribal rural areas). Within the state, top 10 districts/urban ward with high prevalence of NCD and having well-established and functional health facilities and ongoing functional NCD program for a minimum of two years were identified based on the NFHS 5 data. Additionally, identification was also done in consultations with the nodal officers of the state government. The district and block selection were also aided by field level/ first-hand information provided by members of PHRN who have been working in the field and are familiar with the public health system, communities and NCD prevalence.

[1] At the time of data collection, the term in use was AB-HWC. This is the term that was used in the proposal, MoU, letters sent to the government by NHSRC, the tools, interviews, and the analysis. Thus, the researchers have used this term to maintain the consistency. Subsequently during November 2023, AB-HWCs was renamed as Ayushman Arogya Mandir.

The table and chart below shows, prevalence of diabetes and hypertension in the study sites

	Blood sugar level - high or very high (>140 mg/dl) or taking medicine to control blood sugar level (%)- Women			Blood sugar level - high or very high (>140 mg/dl) or taking medicine to control blood sugar level (%)- Men			Elevated blood pressure (Systolic ≥140 mm of Hg and/or Diastolic ≥90 mm of Hg) or taking medicine to control blood pressure (%)- Women			Elevated blood pressure (Systolic ≥140 mm of Hg and/or Diastolic ≥90 mm of Hg) or taking medicine to control blood pressure (%)- Men		
	Urban	**Rural**	**Total**	**Urban**	**Rural**	**Total**	**Urban**	**Rural**	**Total**	**Urban**	**Rural**	**Total**
India	16.3	12.3	13.5	17.9	14.5	15.6	23.6	20.2	21.3	26.6	22.7	24.0
Assam	16.6	12.1	12.8	20.4	15.2	16.0	22.5	18.5	19.1	23.8	19.6	20.3
Chhattisgarh	12.1	8.1	9.0	12.8	10.3	10.8	23.5	23.6	23.6	27.8	27.7	27.7
Delhi	12.3	10.8	12.2	14.0	14.8	14.1	24.2	20.2	24.1	32.8	31.0	32.8
Jharkhand	12.5	9.5	10.2	15.8	13.4	14.1	20.1	17.0	17.8	25.3	21.6	22.6
Odisha	17.4	13.3	14.0	20.3	16.4	17.0	24.5	21.9	22.4	29.3	24.9	25.6

Source: NFHS 5



The findings of the study shed light on the specific circumstances and factors influencing treatment adherence for diabetes and hypertension in each region. Overall, the proportion of patients that took medicine daily for the week preceding the survey stood at a high 81%. The study clearly demonstrates that the HWCs are fully able to conduct the NCD programme relevant to Diabetes Mellitus (DM) and Hypertension (HT) well at primary level provided there is proper health sector governance, as exemplified very convincingly by the case of Assam where there is a near-100% utilization of HWC services with high Treatment Adherence (TA) and low Out of Pocket Expenditures (OOPEs) at one of the HWCs. However, even within Assam, the theoretical sample of a poorer performing HWC with specific challenges of access clearly demonstrates the poorer outcomes on access to medicines and thus on TA. Even for the well-functioning HWC, the data on medicines being always available could be improved from 71%, and saturation was not complete at the time of the study with certain households/hamlets getting left out for geographical and/or social reasons. These included vulnerable individuals such as the elderly as well as specific categories of patients such as those needing insulin or special care for complications such as dialysis.

Despite being in a similar rural area, the HWCs of Jharkhand perform poorly in stark comparison on every indicator; diagnosis at the HWC (14%), follow up at HWC (22%), availability of medicines (50%) and taking medicines from the HWC (22%). The net result on treatment adherence remains more or less the same, however, coexisting with high utilization of private services as well as high frequency of OOPEs specially on medicines and travel.

Significantly, the ASHA/Sahiyya/Mitanin programme manages to circumvent the problems affecting the HWCs, if any, and out-performs the facilities at the level of the community in the same context. Thus, even in the relatively poorly performing Jharkhand, 57% of the respondents needing assistance to understand treatment plans reported help from ASHA/ Sahiyya, 65% of respondents in Jharkhand said that ASHA visited them for follow up of which 79% patients said ASHA visited monthly. In the better-performing rural areas the ASHA programme also did expectedly well. On the whole, the ASHA programme was found to contribute very significantly to enabling TA by maintaining lists and records, counselling patients, assisting in understanding treatment options and facilitating follow-up.

The well-functioning public sector services appear to outperform the private sector amongst all sites in terms of ease of access, waiting times and availability of drugs as well as significantly on OOPE as expected. Wherever decent public health services are available, evidence suggests that people opt to avail them – as exemplified by the mix of private and public services being used in the sites other than Assam. Even in Jharkhand where the dependency on private sector is high, many more people use the HWC for BP and BS testing than do for treatment, simply because the latter is not as available, with 58% of patients getting their blood pressure test done monthly at the HWC as compared to 28% taking medicines from the same. In all areas, much greater intervention is required to achieve treatment adherence for non-pharmaceutical methods of control; namely achieving changes in diet, exercise and substance abuse.

Recommendations:

1. Since the availability of well-functioning HWCs comes up as the most important and primary factor enabling treatment adherence, governance of the Ayushman Bharat (AB) programme emerges as the single most important factor.
2. Clear direction needs to be given to reinforce the population-level coverage of the programme with constant effort to identify those that are being left out of registration, regardless of individual choices of service provider. Specific direction and focus needs to be given to register private sector users within the public health system in a more systematic manner though it was found to be happening in some HWCs already.
3. Even within well-functioning HWCs, and for all HWCs; specific direction is required to ‘reach the last mile’ of households getting left out for geographical or social reasons and to do that not last, but first. This will require specific instruction, action plans, effort and monitoring.\
4. Supply side issues for medicines; adequate quantities and frequency need to be monitored more closely for even better treatment adherence on a daily basis.
5. With the HWCs, special attention is needed to enable regular insulin supplies and create mechanisms such as utilizing community commons for storage. Skills for use of insulin need to be enhanced as well creating community volunteers for assistance to the elderly and disabled persons unable to manage injections.
6. Urban areas experience a specific challenge for monitoring and follow-up. This cannot be achieved without hub and spoke models and full-fledged primary health care systems at the level of the community. Dispensaries and mohalla clinics need a full up-gradation to cover the entire primary care requirements of diabetes and hypertension before treatment adherence can be even examined or evaluated.

7. ASHA programme needs to be fully implemented in urban areas to enable TA considering the complexity and multiplicity of factors affecting TA at household level.

   Notable, the interventions above could significantly bring down OOPEs and enhance TA related to diabetes and hypertension.

8. Special effort is needed to provide access for the elderly in every community and enable TA. Interventions such as the provision of a better path, wheelchairs at the HWC and mobilising village youth volunteers that could help the elderly with coordination as well as transport, need to be facilitated by the primary health care teams.
9. Specific interventions need to be planned to enable Participatory Learning and Action (PLA) on social determinants of NCDs; namely diet, exercise and substance abuse. Wellness activities could be a good starting point but need to include community-based action towards creating community resources alongside behaviour change at an individual level. NGOs with skills in these areas may be employed to showcase models for this.
10. The lack of trust between community and public health systems being a bidirectional issue, requires a 'systems' understanding of health seeking behaviour by the health care providers. The results of this study can help the process of appreciating that patients do take responsibility for their own care if circumstances permit; and appreciate and use government services if they find them helpful and effective. Breaking through previous negative experiences by the community would also need a process of re-establishment of trust (for instance in the case of Jharkhand) which is enabled by processes such as exposure visits to the HWCs by community groups: school children, Self-help groups (SHGs) etc to appreciate it as a community resource.

1. Introduction

Non-communicable diseases (NCDs) are considered to be a silent epidemic in the current phase of epidemiological transition that India is in, posing a threat to public health in terms of morbidity and mortality, as well as adding to the economic burden of affected families.

As per the World Health Organization (WHO), NCDs account for almost 71% of the total global deaths and kill about 41 million people globally each year. About 82% of all premature NCD deaths occur within LMICs. The total NCD mortality burden on LMICs is around 77% [2]. They are not just a major burden on the public health systems but also contribute to financial hardship in households in many low and middle-income countries (LMIC). [1] [2]

In India, about 5.87 million people die each year from NCDs, accounting for 60% of the total deaths [3]. Evidence shows that the risk of an Indian for premature death between 30 and 70 years of age from any one of the four major NCDs, namely cancer, diabetes, cardiovascular diseases, and stroke was about 23% in 2016 [4]. India is struggling to tackle the rising burden of NCDs due to epidemiological and demographic transitions.

About 27% of the total deaths in India are attributed to cardiovascular diseases of which diabetes and hypertension are the most common risk factors [5]. One of the key contributors to the increasing burden of morbidity and mortality due to NCDs is the poor control status of the patient. Factors that lead to poor control status in patients with NCD include poor adherence to treatment recommendations and lack of integrated care at the system level [6]. The increasing trend of NCD is mainly attributed to changes in lifestyle, unhealthy eating habits, tobacco smoking, rise in alcohol intake, and increased urbanisation that has resulted in the growing number NCDs in India [10]. Control of NCDs requires integrated actions across both medical as well as social aspects that influence health. Systems-wide efforts to improve the social determinants of health have still not been mainstreamed in our country. Within the health system, localized actions for community health have been envisaged to address the social determinants of health. Provisions to enable localized actions include the constitution of Village Health, Sanitation and Nutrition Committee (VHSNC)/Jan Arogya Samiti (JAS)/Mahila Arogya Samiti (MAS). However, challenges in implementing and leveraging the existing provisions exist, one lacking inter-sectoral convergence. Social determinants shape the distribution of behavioural risk factors, trigger stress pathways, are linked to environmental exposure to pollutants, and influence the secondary prevention, diagnosis, and treatment of NCDs. The importance of primary healthcare in addressing the various social and biomedical factors associated with poor control status for NCDs cannot be overemphasized. Thus, primary care is the best avenue for delivering NCD care in the most integrated and comprehensive way.

Intense efforts have been taken by the Government of India to effectively plan interventions and strategies related to tackling the burden of NCDs. The Government of India launched the National Programme for Prevention and Control of Cancer, Diabetes, Cardio-vascular Diseases and Stroke (NPCDCS) in 2010 to strengthen the infrastructure and build capacities of human resources, health promotion, early diagnosis, management, and referral. India is the first country to align national targets of NCD in line with the global NCD action plan. The government has introduced various interventions under the NCD program, such as counselling, regular follow-up visits, patient support groups, etc to enhance treatment adherence among patients suffering from diabetes and hypertension [29] [30] [7].

Further, Health and Wellness Centres (HWC) were inaugurated in 2018 to strengthen primary healthcare program and deliver universal, comprehensive, and free primary healthcare. With the introduction of HWCs, the range of services for NCDs expanded to prevention, screening, treatment, management, and control including follow-up for treatment adherence. A new cadre of healthcare providers called the Community Health Officers were also introduced to provide these services. To enable services for NCDs, population-based screening, point-of-care testing, and availability of drugs are made available at

the HWC. Facilities like free medicines, diagnostics, and referral transport are also included in the HWC mandate. Training modules and guidelines have been developed for capacity building of the health care providers- Accredited Social Health Activist (ASHA), Community Health Officer (CHO) and Medical Officer (MO) and the Community-Based Assessment Checklist (CBAC) has been assigned for the identification and referral of patients with NCDs. ASHAs and ANMs have been trained to undertake health promotion and follow-up activities for treatment adherence in the community and to ensure the continuum of care [11] [31].

Interventions planned for treatment adherence under universal screening of NCDs are as follows [29] [30]:

- Individual and family members counseling for treatment compliance by the CHW
- ANMs are assigned the task of conducting IEC/BCC activities for health promotion and ensuring follow-up management for NCD patients. They are also responsible to monitor the supply of drugs, periodic check-ups, etc.
- ASHAs are assigned the task of ensuring regular supply of drugs, and referral of patients to MO in case of any complications. A 5-day training for ASHAs on NCD management, accompanying patients for consultations, creation of patient support groups, and monthly follow-up visits.
- To ensure adherence, formats are designed for ASHAs to record details related to treatment compliance.
- To minimize OOPE, free drugs, and diagnostic service schemes are running under NHM.

1.1 Rationale

The study was conceptualized and developed following an invitation from the National Health Systems Resource Centre intending to promote research projects that are more focused along the lines of applied research with the ultimate aim of translating research into action to protect and promote the health of individuals and community members. The study was conducted under the IR-HSS platform of the MoHFW in collaboration with NHSRC.

India has made huge strides in responding to NCDs. However, the high burden of NCDs demonstrates challenges in the implementation of national guidelines at the ground level. An attempt is being made to establish equitable and affordable primary care prevention, treatment, and support systems for NCDs at the primary and community levels including HWCs, PHCs, ASHAs, and ANMs. However, identifying gaps and solutions at different levels of implementation is important for developing a sustainable NCD care delivery.

With this background, a multi-centric mixed-method study was invited to assess the proportion of treatment adherence and identify its major socio-economic, health systems, condition-related, therapy-related, and patient-related factors among people living with diabetes and hypertension. The study has been conducted to help in planning targeted interventions to address the issue of poor treatment adherence.

1.2 Literature review

Non-communicable diseases in India

India has been facing a double burden of communicable and non-communicable diseases and an increased prevalence of chronic diseases [12]. As per the National Family Health Survey (NFHS) 5 data in India, 13.5% of women and 15.6% of men have high or very high blood sugar levels or taking medicine to control blood sugar. The prevalence of elevated blood pressure levels is more in men (24%) compared to women (21.3%). The prevalence of both diseases is higher in urban areas. There has been an increase in both the disease over the last two NFHS rounds – the prevalence of blood sugar has

increased by 3.5 percentage points in women and 3.3 percentage points in men whereas blood pressure has increased by 3.8 percentage points in women and 3.4 percentage point in men.

The Global Status Report on NCDs, 2014, WHO, showed that in India, 66% of all deaths occur due to NCDs (WHO 2014). A more recent finding by ICMR-INDIAB suggests a high national prevalence of diabetes, pre-diabetes, and hypertension- 11.4%, 15.4%, and 35.5% respectively in the country [14]. The report claims that there are currently 101 million people with diabetes and an additional 136 million people with prediabetes, with Goa having the highest prevalence of diabetes and Uttar Pradesh, having the lowest [14] [32]. The International Diabetes Federation estimated that India has a higher number of people with diabetes than any other country, with estimates ranging from 19.4 million in 1995 to 72.9 million in 2017 [8]. Hypertension is also becoming a major disease, especially in southern India, with its prevalence being above 30% in all the southern states [32]. The increasing prevalence of diabetes and hypertension is a driver as well as a consequence of the epidemiological transition [15]. It is also anticipated that the prevalence of these two conditions is likely to keep rising in the future due to the rapidly aging and urbanization population and 'improving' living standards [15].

It is a general notion that the prevalence of NCDs among the tribal and rural population is comparatively less as compared to the non-tribal population. In rural areas, the prevalence of blood sugar level - very high (>160 mg/dl) for women is 5.5% whereas for men it is 6.5% and hypertension is 5.2% for women and 5.5% for men [9]. However, some studies have found that the burden of NCDs among the tribal population is higher. For instance, a study conducted in Chhattisgarh and Madhya Pradesh found that the tribals had a higher proportion of severe hypertension than non-tribals. [33]. The lack of accessibility to health services and a general notion of the lesser prevalence of NCDs among the PVTG population often leads to negligence of the NCD burden among these populations [16]. The demographic, cultural, and dietary habits vary among the PVTG, rural, urban, and slum populations [33] and context is an important consideration for understanding various elements of NCD interventions that might be required, including treatment adherence.

One of the key contributors to the increasing burden of morbidity and mortality due to NCDs is the poor status of control of the illness leading to acute and long term complications. Factors that leads to poor control status in patients with NCD include poor adherence to disease-management recommendations, lack of integrated care at the system level, and poor compliance with medication [34].

Treatment Adherence -

According to WHO, treatment adherence is the extent to which the patient's behavior in terms of taking medications, following diets, or executing other lifestyle changes coincides with the clinical prescription.

Medication adherence has been defined by the International Society for Pharmacoeconomics and Outcomes Research as the "extent to which a patient acts by the prescribed interval and dose of a dosing regimen".

Past research on NCDs suggests that diabetes and hypertension are two of the most common and behaviourally demanding chronic diseases among NCDs [35] [17]. They require frequent monitoring, dietary counseling, and administration of medication under schedule [18]. Treatment adherence is a common difficulty noticed among people living with these conditions and has been identified as a leading public health challenge. With poor treatment adherence, the health of the patient eventually worsens over time [34] [19]. Adherence to the treatment is essential in preventing complications from NCDs.

Social and structural determinants of health are potential barriers to treatment adherence. Evidence has shown that lack of education, economic stability, access to quality health care, social support, housing, physical environment, nutrition, and behavioral factors are associated with treatment adherence [36]

[37]. The WHO Commission on Social Determinants of Health suggests that these determinants are responsible for the pattern of distribution of mortality and disability from NCDs [20]. Adherence to treatment recommendations is a common and potentially modifiable cause of inadequate control of NCDs. A comprehensive approach is the need of the hour to address all the multi-dimensional factors affecting treatment adherence and control the burden of NCDs.

Evidence suggests that various mechanisms have been adopted around the globe to improve treatment adherence and control NCDs however compliance with the treatment remains low [39].

Existing literature shows multiple lacunae in terms of exploring the different dimensions of treatment adherence, especially in contexts of special socio-economic vulnerability. Perspectives of the healthcare providers and the patients are scarcely found in the literature [40]. There is a paucity of studies on treatment adherence among different contexts and communities such as urban poor, slum dwellers, rural populations, and tribal communities [41] in India.

Adherence to Hypertension Treatment

Evidence suggests that 4 out of 10 adults over 45 years of age in India are not aware of their hypertension status, and of those who are aware, 73% are currently taking medication, and only 10% of these have their hypertension in control [21].

Hypertension is a largely asymptomatic condition, due to which, patients, especially those who are younger and more active, may underestimate the necessity of or benefits of treatment [23]. It is seen that the key causes of non-adherence to hypertension therapy include inadequate understanding of the nature of the disease, its symptoms, consequences, and treatment techniques, as well as mistaken beliefs about them [22]. A study conducted in Chennai showed that 28% of the diagnosed persons with hypertension were non-adherent to medications, with the primary reason being that the blood pressure returned to normal. Additionally, most patients were unaware of the consequence of being non-adherent to hypertension medications [42]. Another study in India showed that the reasons behind non-adherence were a lack of knowledge of hypertension and its complications, the absence of symptoms, the high expense of therapy, or low socioeconomic status [24]. The barriers to adherence are multifaceted, influenced by several interrelated and contributing factors at the patient, practitioner, and healthcare system levels, and they can vary based on the patient's profile [23]. Whenever there is evidence of poor adherence, the patient-practitioner interaction is crucial in identifying patient-specific impediments to adherence [23]. Research suggests that in the Indian context, treatment adherence for hypertension can be increased significantly by increasing greater focus on improved physician-patient relationships and communication, expanded access to health care, affordability, and patient education [24].

Adherence to Diabetes Treatment

A study conducted by the Public Health Foundation of India, Madras Diabetes Research Foundation, and Harvard School of Public Health found that only 52.5% of people with diabetes were aware of their disease status whereas only 40% sought treatment and 24.8% had it under control.7 [21]. Another cross-sectional survey in India with a final sample of 904 adults with Diabetes mellitus (DM) found that 45.8% were aware of their diabetes status, 36.1% were on treatment for their diabetes and 15.7% had it under control [43].

Studies conducted on diabetic patients in India as well as worldwide have found that more than 50% of patients are non-adherent to antidiabetic medications [25] [44]. Successful treatment of diabetes is often challenging. Patient compliance with treatment is essential for it to be effective and to prevent long-term complications of the disease. Benjamin et al in their paper have used the Theory of Planned Behaviour (TPB) to understand patient compliance behavior in a mobile healthcare system. The basic idea of TPB is that attitudes are the driver of intentions, which in turn result in actual behavior [45]. The study found positively associated with the TPB model wherein it was seen when it comes to treatment compliance,

attitudes were strongly correlated with intentions, and these intentions were correlated with actual treatment compliance behaviors. Cameron C. explains the social and psychological factors that influence patient compliance with treatment- doctor-patient relationship and patient satisfaction, communication, social support, health beliefs and attitudes, and duration and complexity of treatment [46]. Diabetes treatment requires strong behavioral changes. Routine medication administration, dietary adjustments, exercise, and self-monitoring of blood glucose (SMBG) are essential parts of the treatment of the disease, often making it difficult for patients to adhere to them [26].

In India, factors related to non-adherence to diabetes include lower per capita monthly expenditures, irregular blood sugar monitoring, little guidance from medical professionals on managing diabetes, non-replenishment upon medicinal stock exhaustion, and lack of family member assistance [27] [47].

The NCD context in the study sites

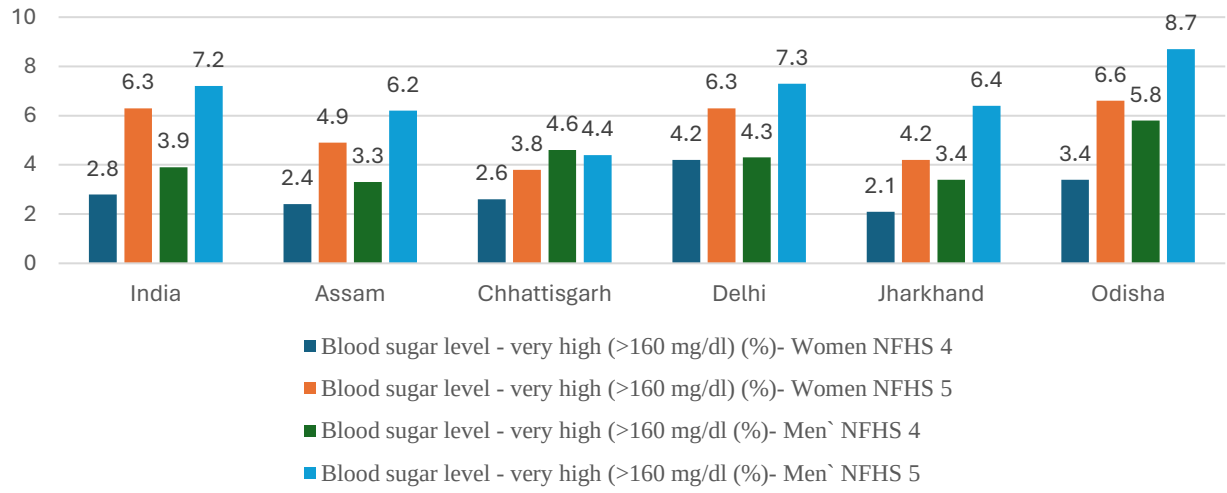
The research study was conducted in Assam (Rural and tribal), Chhattisgarh (Non-tribal rural areas). Delhi (Tier-1 city, Urban slum), Jharkhand (Tribal rural area), and Odisha (Tier- 2 city). Within these states specific sites of Dhubri, Rajnandgaon, Central Delhi, Ranchi and Puri respectively were further selected as the districts that would house the HWCs to be studied While the study sites, selection etc are covered in the section on methods, a brief description of the status of diabetes and hypertension is provided here to highlight contextual nuances.

Table 1: Prevalence of diabetes and hypertension in the study sites

Indicators	Blood sugar level - high or very high (>140 mg/dl) or taking medicine to control blood sugar level (%)- Women			Blood sugar level - high or very high (>140 mg/dl) or taking medicine to control blood sugar level (%)- Men			Elevated blood pressure (Systolic ≥140 mm of Hg and/or Diastolic ≥90 mm of Hg) or taking medicine to control blood pressure (%)- Women			Elevated blood pressure (Systolic ≥140 mm of Hg and/or Diastolic ≥90 mm of Hg) or taking medicine to control blood pressure (%)- Men		
	Urban	**Rural**	**Total**	**Urban**	**Rural**	**Total**	**Urban**	**Rural**	**Total**	**Urban**	**Rural**	**Total**
India	16.3	12.3	13.5	17.9	14.5	15.6	23.6	20.2	21.3	26.6	22.7	24.0
Assam	16.6	12.1	12.8	20.4	15.2	16.0	22.5	18.5	19.1	23.8	19.6	20.3
Chhattisgarh	12.1	8.1	9.0	12.8	10.3	10.8	23.5	23.6	23.6	27.8	27.7	27.7
Delhi	12.3	10.8	12.2	14.0	14.8	14.1	24.2	20.2	24.1	32.8	31.0	32.8
Jharkhand	12.5	9.5	10.2	15.8	13.4	14.1	20.1	17.0	17.8	25.3	21.6	22.6
Odisha	17.4	13.3	14.0	20.3	16.4	17.0	24.5	21.9	22.4	29.3	24.9	25.6

Source: NFHS 5

Chart 1: Prevalence of diabetes in the study sites (NFHS 4&5)



Status of diabetes and hypertension in specific study districts:

Dhubri is a southwestern district of Assam. When compared with the state and national average, the district has slightly better trends for both diabetes and hypertension. Almost 10.4% of men and 8.2% of women have high or very high blood sugar levels or taking medicine to control blood sugar levels. Similarly, 19% of men and 18.2 % of women have elevated blood pressure or taking medicine to control blood pressure.

Rajnandgaon district in Chhattisgarh that was formed in 1973. Most indicators of the district for diabetes and hypertension are higher than the state average. Elevated blood pressure or taking medicine to control blood pressure rates in the district for men and women is 28.3% and 27.7% which is higher than both state and national levels. In case of high blood sugar levels, or taking medicine to control blood sugar levels, the data suggests that in men it is 8.2% which is lower than the state average.

On comparing the statistics of Central Delhi with the state and national average, it was seen that the trends for diabetes are almost similar. However, when it comes to hypertension, central Delhi showed a higher prevalence than the state and national levels. Men and women having high or very high blood sugar levels (>140 mg/dl) or taking medicine to control their blood sugar levels 15.8% and 11.7% respectively. Elevated blood pressure (Systolic ≥140 mm of Hg and/or Diastolic ≥90 mm of Hg) or taking medicine to control blood pressure is 41.5% among men and 26.5% in women.

In the case of Ranchi, though the diabetes rates are lower than the national and state statistics, however, hypertension is higher when compared with the state average. High or very high (>140 mg/dl) blood sugar level or taking medicine to control blood sugar level persists among 12% of men and 9.7% of women in Ranchi. Around, 23.1% of men and 19.6% of women in Ranchi have elevated blood pressure (Systolic ≥140 mm of Hg and/or Diastolic ≥90 mm of Hg) or taking medicine to control blood pressure.

Puri is a coastal district of Odisha. The district shows higher trends for diabetes but lower for hypertension when compared with the state and national averages. 23.1% of men and 20.7% of women in the district have high or very high blood sugar levels (>140 mg/dl) or taking medicine to control their blood sugar levels. Men and women having elevated blood pressure (Systolic ≥140 mm of Hg and/or diastolic ≥90 mm of Hg) or taking medicine to control blood pressure in Puri is 23.5% and 20.8% respectively.

1.3 Conceptual Framework

The study has adapted the conceptual framework devised by the World Health Organization in 2003 (Figure 1). The framework classified the factors affecting treatment adherence of patients to chronic diseases into five dimensions. These dimensions are factors related to the patient, factors related to the treatment, factors related to the health system, socioeconomic factors, and factors related to disease conditions [28].

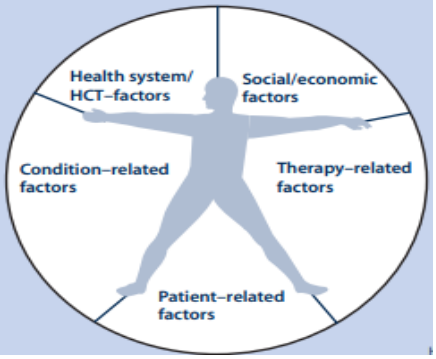


Figure 1: WHO framework on five dimensions of adherence

Deriving from WHO's conceptual framework, the themes of interest in this study included patient-related factors like nutrition, transportation, cost, perception of susceptibility to disease severity or death, knowledge of disease; treatment-related factors like complexity of treatment regimen, drugs availability, drug frequency; healthcare systems related factors like access, supply of medicines, patient-provider relationship, availability of personnel, training and capacity building of health personnel, continuity of care, counselling of diet and lifestyle modification etc; condition related factors like severity of symptoms, co-morbidities and socio-economic factors like age, gender, education, income social support, etc. The study has assessed the roles of these factors in treatment adherence with a focus on primary-level healthcare in different contexts.

2. Methods

The study is a mixed methods study using a quantitative survey and qualitative methods of observation, FGDs, Case studies and Key Informant interviews as further described.

2.1 Aim and objectives of the study

To assess the proportion of treatment adherence for diabetes and/or hypertension and identify factors associated with treatment adherence by vulnerable & marginalised communities in India.

Specific Objectives

- To assess the proportion and describe the enablers and barriers affecting treatment adherence among patients diagnosed with diabetes and/or hypertension at health facilities in selected study sites with varying contexts.
- To examine the implementation of interventions planned for treatment adherence under universal screening of NCDs in different settings.
- To formulate general and context-specific recommendations to increase treatment adherence to Hypertension and Diabetes

2.2 Study location

The research study was conducted in Delhi (Tier-1 city, urban slum), Puri district in Odisha (Tier- 2 city), Assam (Rural and tribal), Jharkhand (Tribal rural area), and Chhattisgarh (Non-tribal rural areas). The study sites from different parts of the country and different set-ups were selected to provide a more representative sample so that the results of the study can be extrapolated to a broader section of the population. Convenience of having experienced researcher and recommendation also made by NHSRC for selection of states. While it was expected that the Assam site may have a mixed rural population, recommendations by the State officials were to be taken into account and eventually a 'good practice' nontribal rural area was selected for Assam (Piazbari). This was supplemented by the selection of a relatively more challenging area (Khankhowa) in the same district as a theoretical sample for comparisons. Various indicators of place of current treatment, place of current medication, follow-up visits, OOP on medicines, and access to medicines were compared. Overall there were some differences between responses from the two villages of which the major ones have been presented.

In Jharkhand though we had anticipated covering a Particularly Vulnerable Tribal Groups (PVTG) population, but the final selection as per the process described below, reflected a non-PVTG tribal, rural population.

2.2.1 Selection of districts

Within the state, top 10 districts/urban ward with high prevalence of NCD and having well-established and functional health facilities and ongoing functional NCD program for a minimum of two years were identified based on the NFHS 5 data. Additionally, identification was also done in consultations with the nodal officers of the state government. The district and block selection were also aided by field level/ first-hand information provided by

members of PHRN who have been working in the field and are familiar with the public health system, communities and NCD prevalence.

2.2.2 Selection of block and Health and Wellness Centres /Urban Primary Health Centres

Well-functioning primary level health care facilities (HWCs and UPHCs) where the NCD programme has been operational for more than two years were to be chosen. A maximum of four health centres per site were to be visited to reach the target sample size. However, the sparse distribution of patients in Jharkhand necessitated increasing the centres to eight in that site. Though preference was to be given to areas where organisations were already working to enable continuity of health care support in the communities, in fact we are were not able to find any in our selected areas.

In Assam, the study was conducted in the Raniganj block of Dhubri district. Three HWCs namely - Piazbari, Khankowa, Ambari were selected. The selected area represented different populations, including minority, and mixed caste groups.

In Chhattisgarh, the study was conducted in Rajnandgaon block of Rajnandgaon district. Rajnandgaon is inhabited by a non-tribal population. Three HWCs were identified based on their status of implementation of the non-communicable disease programme. The HWCs covered are namely Baghera, Rengakathera, Singhola.

In Delhi, the study was conducted in an urban slum in Central Delhi/ Chandni Chowk ward. The area was selected through an in-depth discussion with the nodal officer at the department of health, Government of National Capital Territory (NCT) Delhi and the Director General at the Directorate of health services. A list of Delhi Government Dispensaries was obtained and based on that the study was conducted in Ajmeri Gate Delhi Government Dispensary (DGD), Dujana House, Gali Samosan.

In Jharkhand, the study was conducted in Ratu block of Ranchi district. The block was selected by the working group given the criteria proposed for the study. In Jharkhand a total of nine HWCs were covered to achieve saturation. The HWCs considered for the study were - Tundul, Tarup, Tiril, Nayasarai, Lalgutwa, Katarpa, Tusmu, Bandhya, Barsa.

In Odisha, the study was conducted in urban slums of Puri district. Puri was selected based on our past experience of working in Puri on health and nutrition issues. To finalise the wards and slums, the study met the MO in charge and the NCD nodal officer. The study area was finalised in consultation with a health official at the district level. The study was conducted in Dolabedikona/ Penthakata and Baliapanda slum areas.

Table 2: List of district/blocks/facilities selected for the study

State	District	Block/ward	HWC/UPHC/DGD	Population
Assam	Dhubri	Raniganj	1. Piazbari 2. Khankowa 3. Ambari	Rural areas with Muslim population
Chhattisgarh	Rajnandgaon	Rajnandgaon	1. Baghera, 2. Rengakathera 3. Singhola	Rural areas with non-tribal population.
Delhi	Central Delhi	Chandni Chowk	1. Ajmeri Gate DGD 2. Dujana House, Gali Samosan DGD	Low socio-economic background, under privileged urban population.
Jharkhand	Ranchi	Ratu block	1. Tundul 2. Tarup 3. Tiril 4. Nayasarai 5. Lalgutwa 6. Katarpa, 7. Tusmu, 8. Bandhya	Rural areas with and tribal population
Odisha	Puri	Puri City	1. Dolabedikon/ Penthakata, 2. Baliapanda	Urban slum, under privileged population

2.3 Study design

This study has applied mixed methods to identify factors associated with treatment adherence among patients suffering from diabetes and hypertension. Both quantitative and qualitative components. have been used to obtain comprehensive information on various factors associated with the adherence of treatment for diabetes and/or hypertension and barrier and challenges for implementation of NCD programme.

2.4 Tools for data collection

Area mapping: Area mapping was conducted in all the 21 Health and Wellness Centre areas to understand the socio demographic features and resource availability.

Patients list: The list of patients obtained from the HWCs was organised and used to contact the patients for the patient survey.

Patient survey tool: A structured patient survey tool was constructed to obtain comprehensive information on various factors associated with the adherence of treatment for diabetes and/or hypertension and used to interview patients with Hypertension or/and Diabetes. The survey tool consisted of sections related to patient profile, general and household information, information regarding diagnosis of disease, treatment plan and adherence, attitude of patients towards the treatment plan and follow-up, availability and access to services at the HWCs/UPHCs, experience with the health workforce and patient support.

Focus group discussions checklist: A focussed group discussion checklist was developed for ASHAs (known as Sahiya in Jharkhand and Mitanin in Chattisgarh)/ Community health workers. The tool was used to understand the role of ASHA/CHWs in the NCD programme,

their role in treatment adherence and related procedures, training and support systems, problems and challenges.

Interview guide for key informants: A semi- structured interviews guide was used to collect information from healthcare providers at primary facility level, and district and state officials. The tool focussed on understanding the situation of NCDs in the study area, nature of services provided by the public health system and heath care providers, treatment adherence for diabetes and hypertension, challenges, and barriers.

Case studies: Case studies were done for selected patients identified by the state team to detail specific and key gaps and issues associated with treatment adherence.

Facility Survey: A pre-structured, pre-tested facility survey checklist was used was to assess infrastructure, inventory management, diagnostics, availability of drugs/medicine, human resource and service availability at the HWC/UPHC.

2.5 The pilot study

A pilot study was conducted in various states and contexts to assess the tool's effectiveness and identify any areas for improvement. The study was conducted in Delhi, Jharkhand, and Chhattisgarh. Based on the learnings from the pilot testing, the team members shared their observations, and changes were made to the tool using a peer review method among the research team. During the pilot survey, it was observed that given the length of the survey tool, it was time-consuming while administering. Based on this experience and recommendations from NHSRC, the tools were revised, and the questions were reduced to 66 from 109. Similarly, the ASHA FGD checklist was also pared (from 36 questions to 13 questions).

This collaborative approach ensured that the final tool was comprehensive, usable, and reflected the team's collective expertise. The final tool was shared with and approved by the Principal Investigators (PIs).

2.6 Sampling and sample size

Table 3: Sample Distribution

Category	**Sample size per site**	**Total as per proposal**	**Total achieved**
No. of HWCs/UPHC to be covered	Max 4	Max 20	18
No. of patients	273 (128 for diabetes and 145 for hypertension)	1365	1469
Focus group discussions with ASHAs	4	20	13[2]

[2] The reasons for not achieving the target- Only two FGDs could be conducted in Delhi as during the data collection period the ASHAs were on strike. In Odisha only one FGD was done as the ASHA were not willing to participate. Moreover through the numbers achieved it was also found that the data was saturated.

Key Informant interviews: (ANM, CHO, MO at UPHC/DGD, Block/PHC level Medical officer, State and district nodal officer Civil society/Public health expert Pharmacist at UPHC/DGD Others)	Approximately 4 * May vary based on context, some sites may have more KII interviews as the study progresses	20	21

The patients diagnosed for diabetes and/or hypertension registered and availing treatment in the selected HWCs/UPHCs were selected. The sample population included all the patients above age 18 years with diabetes and/or hypertension registered at the selected health facilities and has been taking treatment. The sample size has been calculated with the following assumptions to be able to differentiate between the selected contexts:

The national prevalence of diabetes to be 14.5 based on NFHS-5 survey.

The national prevalence of hypertension to be 22.6 based on NFHS-5 survey.

The average national block level population= 100000

Proportion of patients registered in a public health facility at block level where an NCD programme has been running for a minimum of two years to be 50%,

Based on the above calculations, and assuming the proportion of patients with medicine adherence for diabetes to be 69% [48] with alpha error of 8% and 95% CI using Open Epi version 3.01 the sample size calculated for patients with diabetes was 128 per site with a total of 640 across study site.

Based on the above calculations, and assuming the proportion of patients with medicine adherence for hypertension to be 59% [48] with alpha error of 8% and 95% CI using OpenEpi version 3.01 the sample size calculated for patients with diabetes was 145 per site with a total of 725 across study sites.

Hence the total sample obtained for medicine adherence for both diabetes and hypertension was calculated to be 1365 (273 per site).

2.7 Selection of patients for the survey

A master list of patients was obtained from the HWCs/UPHCs in Assam, Chhattisgarh, Jharkhand and Odisha. No such list was available in Delhi and support had to be taken from the ASHAs of the selected areas. The ASHAs provided the details of the patients from informal sheet/notes that were available with them who were then contacted by the research team.

In Odisha, the data obtained from UPHC was not updated or was incorrect and did not corroborate with patients in the field. In this case it was decided to conduct a door-to-door patients survey in the selected UPHC area.

Of the total of about 4500 patients thus identified over four study sites and 18 HWCs the following were surveyed at convenience and availability till samples required were fulfilled:

Table 4: Patients survey conducted across study sites.

States	No of patient interviews
Assam	309
Chhattisgarh	278
Delhi	303
Jharkhand	304
Odisha	275
Grand Total	**1469**

Key informant interviews were conducted with the health care providers and frontline workers such as ANM and other facility level health staff. A total of 20 Key Informant interviews (KII) were planned with the health care providers and experts across locations and finally, 22 KII were conducted for this study. Since ASHA's are mainly allotted with the task of undertaking follow-up for treatment adherence and enable lifestyle changes, focused group discussions were done with the ASHAs to assess the current level of knowledge and practices for NCDs based on the ASHA modules and identify the issues and gaps associated with treatment adherence at individual, community, and facility level. A total of 96 ASHAs participated in the FGDs.

Table 5 : Key informant interview, FGDs and case studies conducted across study sites

State/Respondent type	Assam	Chhattisgarh	Delhi	Jharkhand	Odisha	Total
Key informant interviews						
HWC/ UPHC/ health facility level staff	1	4	3	2	2	**12**
District level officials	1	2	1	0	0	**4**
State level officials	1	1	1	0	0	**3**
Civil society/Public Health Experts	1	2	0	0	0	**3**
Total- KII	**3**	**9**	**5**	**2**	**2**	**22**
Focus Group Discussion with ASHAs	4	2	2	2	1	**11**
Case studies	5	3	4	3	2	**17**

2.8 Training of survey team

As part of the research process, the research team attended an internally conducted training session on the NCD scenario in the country. The aim of the training session was to provide an overview and build the technical capabilities of the team for conducting the study. The training covered a range of topics related to the NCDs, including the epidemiology of NCDs in the country, current NCD control and prevention strategies, and the use of data for NCD research and program planning. The training provided the team with an in-depth

understanding of the NCD scenario in the country and the context in which the study would be conducted. This helped the team to develop the necessary knowledge and skills to design, implement, and analyze the study. The training was an important step in the research process, as it helped to ensure that the study was conducted in a rigorous and scientifically sound manner.

The team also conducted several training sessions to equip their Research Assistants and Field Investigators with the necessary skills to carry out their roles effectively. This included training on NCD and the patient survey tool, as well as qualitative tools. To ensure that ethical considerations were given the utmost importance throughout the research process, the team conducted an ethical training session with the entire team prior to data collection.

2.9 Data collection, analysis and management

A quality check protocol was developed and sent to the state teams to ensure quality of the patient interviews data during the quantitative data collection. After completing the patient interviews in hard copy format, data was entered in a Kobo toolbox by the field investigators. The data was reviewed by the research team at PHRN national office.

After the data was collected, data cleaning and analysis was undertaken. The combined data analysis for all five states was done through Microsoft Excel. Graphs and tables were developed based on the broad indicators.

For the qualitative data analysis, detailed notes were taken in local language or audio-recorded. The interviews were translated and transcribed to English. Analysis was manually done based on emerging themes as well as links between themes.

2.10 Study timeline

The one-year research study started in November 2022, with data collection done during June- September 2023.

State	Timeline for data collection
Assam	June- September 2023
Chhattisgarh	June- September 2023
Delhi	July- September 2023
Jharkhand	June- September 2023
Odisha	August- September 2023

The data was collected in approximately 60 days in each study site.

2.11 Ethical considerations

Ethical clearance was taken from the Institutional Ethics Committee of Public Health Resource Society. Participant information sheet and informed consent form was prepared and translated into the local language. They were distributed and read out to all participants of the study after which written or verbal consent was taken. Participation was voluntary with the

rights of the respondents to withdraw at any stage. Informed consent was taken for audio-recording of the interviews and for taking photographs.

Simultaneously, patients or their families who were part of the patient interviews were given information pamphlets on Hypertension and Diabetes. In some states like Chhattisgarh, we found some cases where patients were taking medicines different from their prescription and in a few cases the wrong medication had been mistakenly dispensed; this was informed to the patients and the ASHA/ CHO.

No risks were perceived to the respondents of the study. Confidentiality was maintained throughout data collection, analysis, and documentation in the study. Anonymised identities of respondents have been used in the final report.

Finally, the results of the study will be shared with all the stakeholders. Due acknowledgement will be given to all persons (participants and others) involved in this research.

2.12 Limitations of the study

Since the study universe comprises, patients listed as registered in the public health facilities, any bias of the sample related to unregistered patients cannot be ruled out. It would also be technically incorrect to claim the proportions found to be representative of proportions existing in the community on the whole. However, since there has been a comprehensive process of surveying at the household level (CBAC) it was considered that the registration would be fairly comprehensive. Nonetheless, some unregistered patients were discovered during the study process and have been presented as case studies.

The field researchers were not medically trained and thus not competent to offer opinions on equivalence between various drugs that were being used. However, considering a fairly straightforward medical treatment regimen being used in the NCD programme this was not anticipated to cause a challenge except in patients being treated in the private sector. Nonetheless, some effort was made to have prescriptions evaluated by a doctor on a sample basis for readability, as it was considered important for drug dispensing between multiple providers being used by patients. The focus tightly remained treatment adherence and there was no attempt to look at other important elements such as treatment outcomes.

It is always a challenge to engage with busy community members for research purposes and this becomes even harder when the subject matter is as technical as NCDs and; in particular, treatment adherence rather than the overall personal experience of the illness. Concerns had been raised at the planning stage related to the length of the questionnaire, which, in turn, was related to the need to cover supply side issues, patient related issues as well as the interpretation of ‘treatment’ as not merely medical but also related to living conditions of diets, exercise and substance abuse. However, since the study was attempted in areas and local researchers, this was handled well by the extra effort of making several visits if necessary.

3. Findings

3.1 Study site description

Dhubri, Assam

The study was conducted in the Raniganj block, Bilasipara tehsil, Dhubri district of Assam, India. Raniganj block is located 43 km east of the Dhubri district headquarters with a population of approximately 420,000, of which 52,000 are urban residents and 368,000 live in rural areas. There are 11 Primary Health Centres (PHCs), 48 sub-centres, and 29 HWCs catering to the population's health needs. The demographic composition of Raniganj is quite varied, with a mix of different caste groups primarily engaged in farming, labour, and local vending. The housing in the area is a combination of *pukka* (concrete) and *kutcha* (non-concrete) structures. However, the block faces significant vulnerabilities, mainly due to the high risk of floods, especially in the riverine (*char*) areas. The transportation modes available are tempos, autos, e-rickshaws, bikes, and cycles. In the riverine regions, boats are used to navigate the challenging terrain. Significantly, at the time of the study the area was under a flood alert and the team was able to experience a period of; possibly, the worst access to flood affected areas.

In this region, most individuals own farmland and earn their livelihood by marketing vegetables, fruits, and poultry. There appears to be a high consumption of salt and sugar in the community, and it is common for people to drink tea that contains both salt and sugar. Patients sometimes prefer seeking treatment from traditional healers or purchasing medicines from unlicensed practitioners because allopathic medications are not permanent cures. After an initial visit to a HWC, they often seek further treatment at private clinics or other places. Public transportation options encompass buses, e-rickshaws, boats, and auto-rickshaws. Individuals use cars, motorcycles, and bicycles for private conveyance. The road network includes national highways, unpaved paths, and minor connecting roads. Electricity is accessible in most places, although the 'char' regions are exceptions, lacking this utility. Marketplaces in the area are comprised of small shops and local stalls that open every week, particularly on Thursdays and Sundays, with most of the populace usually traveling to Bogribari (3km from the centre) for their shopping requirements.

Three HWCs were covered in Dhubri: Piazbari HWC, Khankhowa HWC, and Ambari HWC.

Piazbari HWC

In the rural expanse of the Dhubri district, 21 km away, lies Piazbari HWC, serving about 9,101 residents, predominantly from the Muslim community. It encompasses six revenue villages, each with unique housing structures and modes of transportation. Notably, Sadhuvasa Part II village stands out for its riverine location and reliance on only boats for commuting.

One of the significant observations was that the Piazbari HWC CPHC team is performing effectively due to the strong collaboration and long-standing partnership between the CHO and the team members, which is bolstered by good communication and leadership skills. The HWC building looks well maintained and exhibits signs of a professional approach to running health care programmes with posters, tracking sheets, maps etc.

A kitchen garden has been cultivated at the HWC as a model to inspire the local community toward healthy eating habits. By showcasing the growth of fresh green vegetables, the garden serves as a practical example and educational tool for villagers, especially those with conditions like hypertension and diabetes. It emphasizes that consuming fresh greens and vegetables can be a key factor in maintaining good health.

A WhatsApp group for Piazbari HWC was created as a direct channel for disseminating information. Those who are not members of the group receive updates through their acquaintances or neighbours, ensuring widespread community awareness.
ASHAs are often the ones who take the lead with these initiatives. They notify the community about screening schedules and when to visit the Health and Wellness Centre. For subsequent visits, a follow-up card records the next appointment date, prompting patients to return at the appropriate time.

Khankhowa HWC
The Khankhowa HWC serves a population of 7,045 across six villages, with populations ranging from 407 to 1,375. The areas face operational challenges and become inaccessible due to floods. It has limited accessibility, primarily due to its reliance on boat transport and vulnerability to floods. Khankhowa HWC, known for its less effective performance, grapples with significant access issues mainly related to accessibility.

The area served by Khankhowa HWC has been noted to be quite challenging and underdeveloped. Frequent flooding often leads to the HWC being shut down. Additionally, the healthcare staff show a lack of motivation. The absence of roads linking the HWC with external areas forces residents to travel by boat.

Ambari HWC
Ambari HWC, serves six villages. The population ranges from 775 to 1,570 per village. Some villages have poor road connectivity and long commute times to the HWC. The long travel times to the centre suggest challenges in service delivery.

Rajnandgaon, Chhattisgarh
The study was conducted in Rajnandgaon block, Chhattisgarh, covering three HWCs – Bagherra, Rangakathera, and Singhola. The villages and HWCs covered under the study were 10-30 km from Rajnandgaon district and about 80-100 km from Raipur, the capital city. The terrains are plains.

Bagherra HWC
Located approximately 20 km from Rajnandgaon district, Bagherra village has the Bagherra HWC, the most distant among the HWCs covered for the study. Despite being the farthest, the village is serviced by buses and shared autos, although only sometimes. Additionally, the village is home to an Ayurvedic (AYUSH) HWC. Among the three HWCs examined, Bagherra HWC stands out as one of the better-performing centres. It is situated on the main road within the village; it has a dedicated CHO who meticulously maintains records of patients with diabetes and hypertension, contributing to the HWC's effective healthcare delivery.

The Bagherra HWC serves a cluster of villages, each with its own unique characteristics. Bagherra village, the primary location of the HWC, is characterized by dense habitation with concrete houses, though it exhibits a somewhat unplanned layout with narrow lanes.

Tumdilewa village, located 2 km away along the main road, is another village under the HWC's purview.

Mudhipar and Navagaon are adjacent villages 4 km from the HWC Bagherra without direct roads or transportation facilities. Despite this, they display a relatively higher economic profile. Most of the houses in this village are pucca houses with more organized village planning and concrete roads within the village lanes. Previously, these villages were supported by a stone quarry, which is now closed. Most of the people are now working in nearby steel and biscuit factories. A notable aspect of these villages is their reliance on private healthcare over the HWC, primarily due to difficulty accessing the centre.

Kaldabri village is located on the main road and is about 5 km from the HWC Bagherra. It is equidistant from the Community Health Centre (CHC) Ghumka and the HWC Bagherra., Parasbod village, which is 4 km away from the main road, needs more transportation access, making it easier for people to access healthcare facilities.

Rangakathera HWC

Rangakathera HWC village is 10 km from Rajnandgaon district. The HWC Rangakathera is poorly connected among the HWCs covered in the study. Only one or two buses operate in a day. The records and registers at the HWC were not properly maintained. The information regarding the patients for hypertension and diabetes was accessed from the records maintained by the ASHA. The CHO did not appear to have a good rapport with the ASHA and the community, resulting in a lack of trust and faith in the CHO/healthcare provider at the HWC. Availability of medicine and other stock was an issue, as per the information shared by the CHO.

The Rangakathera village cluster, served by the Rangakathera HWC, presents a varied landscape in terms of infrastructure and accessibility. The main Rangakathera village, housing the HWC, is located on the main road, providing easy access for its population. In contrast, Daragaon village, situated 2 km from the main road, is connected via a combination of *kutcha* (unpaved) and *pucca* (paved) roads, indicating a mix of developed and underdeveloped infrastructure. Further away, Makranpur village lies 4 km off the main road, suggesting potential challenges in accessibility for its inhabitants. This variation in proximity to the main road and the nature of road connectivity among these villages reflects differing ease of access to healthcare services provided by the Rangakathera HWC.

Singhola HWC

Singhola HWC was a better-performing HWC among the centres considered for the study. Singhola HWC village is 8-10 km from Rajnandgaon district, situated on the highway, well connected with all the villages under the HWC. The transportation is through buses, which are adequately connected. The CHO had a good rapport with the community members and was available on the phone for the patients. The records and registers were properly maintained for both diabetes and hypertension.

The villagers' main occupation is farming, and the village is termed prosperous (*sampanna*), as it had big farmers. The Singhola village cluster, serviced by the Singhola HWC, showcases diverse communities with unique characteristics. Singhola village itself, where the HWC is located, stands out as the most prosperous and urbanized of all, reflecting a high degree of development. Ranitarai village, situated on the main highway and 4 km from the HWC, benefits from excellent connectivity and frequent bus services, facilitating easy access to

healthcare. Similarly, Maharajpur village, located just 2 km from the HWC on the main highway, enjoys the same level of convenient access.

Alikhunta village is located 3 km away from the HWC. A substantial Muslim population inhabits this village. The main occupation among the people is large-scale farming. Most of the households own, on average, 5 acres of land. There are six households in the villages that own no land.

Bhawarmarra village, however, faces the most significant accessibility challenges given its location. The village is located on the highway, 6 km away from the HWC. The road connectivity is very poor as the road (2-3 km) till the HWC is a kuccha road leading to an access issues. Its proximity to the Shivnath River also poses risks, as heavy rains can lead to flooding, affecting parts of the village and its residents.

Central Delhi district, Delhi

The study was conducted in the Chandni Chowk ward of central Delhi. The dispensaries considered under the study were Ajmeri Gate and Gali Samosan. The area is known for its street food places and wholesale markets and is one of the oldest markets in Delhi. The majority of the population in the area are Muslims.

The population is engaged in a variety of occupations, including daily wage labour, rickshaw pulling, and small-scale selling; often in nearby markets, women mostly work as domestic help. The older people are mostly not employed. The housing profile predominantly consists of pucca houses and single-story buildings, many of which are old and dilapidated. The area faces specific vulnerabilities such as poor sanitation, open drainage systems, and narrow streets, and is predominantly a ‘minority’ community. The district is strategically located near a market area, enhancing its commercial viability.

Public transport is readily available, with options like e-rickshaws and rickshaws, bus service, and the metro and Old Delhi railway station nearby. The commercial landscape is diverse, featuring a range of shops, including butchers, garment stores, eateries, atta shops, bookstores, carpet sellers, hardware and sanitary ware stores, metal shops, chemists, tobacco product sellers, henna artists, jewellery stores, shoe shops, invitation card printers, currency exchange bureaus, Kirana and general stores, sweet shops, confectioneries, cybercafés (offering services like birth certificate and passport processing), advocate firms, guest houses, and travel agents.

Close to the dispensaries are a few private clinics, unregistered medical practitioners, and faith healers. The community also has access to government tertiary care hospitals like Lok Nayak Hospital and Lady Hardinge.

Ajmeri Gate Delhi Government Dispensary (DGD)

The Ajmeri Gate Dispensary is located on the Ajmeri Gate Road in Gali Sitara. It is around one kilometre from the Chawri Bazar metro station. On the main road, there are hardware stores surrounding the dispensary, and once you enter the main Gali (street), there are numerous shops selling safety equipment for industrial purposes. There are a few butcher shops and small eateries selling samosa, puri etc, right outside the dispensary.

The DGD has been built in a building that was once a community centre in the area. It is difficult in terms of accessibility as the dispensary is located on the first floor, making it

difficult for older people, pregnant women, and differently abled to access the facility. The dispensary has two medical officers, two ANMs, and around 18 ASHAs.

The dispensary maintains a register for NCD patients. The MO here initiated this a few years ago. The patients are satisfied with the dispensary's services and with the medical officer's behaviour.

Medicines are mostly available at the dispensary, and if not, then the patients prefer to collect from the nearby dispensaries, which are a distance of about 3km (Dujana House, Ballimaran, Suiwalan, Gali Guiliyan, etc.) from the Ajmeri gate DGD.

Gali Samosan Delhi Government Dispensary
It is located in Lal Quan market in Chandni Chowk, which is equidistant from the Chandni Chowk and Chawri Bazar metro station. It is a wholesale market area. Once you enter from the main road, you have to go further into two *galis* to reach the dispensary.

It is an overcrowded area, with small and big shops all over. The shops available are mostly-small sweet shops, places selling fried snacks, and butcher shops.

The dispensary is built on a space where an MCD (Municipal school) school building was built earlier. The markings were not easily visible to even identify it as a dispensary; even most shop owners around it were not aware. This again had issues of accessibility, where the Dispensary was on the first floor, which could only be reached through stairs. At the time of data collection, the Dispensary was under renovation.
Most of the time, the medicines were available to patients.

No records and registers are maintained for NCD. The ASHA and ANM had recently started entering information on the NCD portal. The details of patients were accessed through the ASHAs working directly with the community. This shows that, to some degree, ASHAs in this DGD are able to fulfil their role in the NCD Programme.

Ranchi, Jharkhand
In Jharkhand, the data was collected from Ranchi district and Ratu block. 7 HWC, 14 villages, and 39 hamlets are included within this. The study was conducted in the catchment villages of Ratu Community Health Centre (CHC). The CHC is located 15 km west of Ranchi district headquarters. Ratu CHC covers around 83 villages of two Community Development blocks, namely Ratu and Nagri, with the support of 22 Health Sub-Centre, 11 Health & Wellness Centres, and two Primary Health Centres. Twelve villages have maternity and child welfare centres, four villages have family welfare centres, and 31 villages have medicine shops.

Ratu CHC covers a population of 153,007(Census, 2011), comprising 50.5% male and 49.5% female. Around 78% of the population is rural (2011 census). There are 27 panchayats with 83 in-habited villages. About 40% of villages have more than 75% tribal population (*Oraons, Mundas* etc).

Most of the villages in the block are connected to block headquarters, while some are far and difficult to access. The majority of houses are *semi-pucca* or *kutcha*. However, many pucca houses are now being constructed in the villages, mostly in villages closer to Ranchi city. The main occupation of the people of this block is agricultural cultivation, and many earn their

living by working as agricultural labourers, unskilled and semi-skilled labourers in construction sites, and in the adjoining small-scale industrial units. Both men and women are equally involved in these activities.

Seasonal migration of male members for unskilled or semi-skilled labour and female members as domestic help was observed. Wage employment of women in the city or nearby areas is one of the major support systems for livelihood among low-income families. Male member's engagement as semi-skilled labourers in cities and nearby areas is more common in the villages near cities.

Most of the sample villages of our study were situated south of CHC Ratu. The closest HWC in our sample was at a distance of 10-12 km, whereas the remotest was 35 km from CHC Ratu.
All the HWCs under our sample were functional in newly constructed buildings. Out of 7 HWCs in our sample, Tundul and Tiril HWCs were not located centrally with respect to their catchment villages. In six HWCs (except Katarpa HWC), the CHO had a record of diabetes and hypertension patients. In all seven HWCs, medicine issues were reported by the CHO and patients interviewed. The study team noted that Katarpa HWC was the poorest performing HWC and was found closed on many days during the study.

Katarpa HWC
Katarpa HWC is the farthest from CHC Ratu, around 30 km southwest of the CHC catchment map. The area has a fair amount of vegetation covered with undulated topography. Public transport in the form of auto-rickshaws is available only on weekly *haat*/market days.

Katarpa, the main village where the HWC is located, is characterized as remote, with an approach road that is a mix of broken *kutcha* (unpaved) and *semi-pucca* (partly paved) paths. The housing in Katarpa varies between *kutcha* and *pucca* (concrete) structures, reflecting a blend of traditional and more modern living conditions.

Kumbhatoli hamlet, a part of Katarpa village, is about 2 km from the HWC. This hamlet is connected to the HWC by a broken/Kutcha road, indicating significant accessibility issues.
Khunta village is located 5 km from the HWC, accessible through a forest approach road made of concrete. This suggests a more secluded setting, surrounded by natural terrain, with a more stable road infrastructure than Katarpa and Kumbhatoli.
Saher village, 3 km from the HWC, is connected by a broken concrete road. While closer to the healthcare centre than Khunta, the road conditions in Saher hinder timely access to healthcare services.

Bandhaya HWC
The Bandhaya HWC and its associated village are located 30 km from the Community Health Centre (CHC), Ratu, in the southwestern part of the CHC's catchment area. Bandhaya is characterized by considerable greenery and a rolling landscape. Public transportation, primarily in auto-rickshaws, is limited to the weekly market (*haat*) days, indicating restricted regular transport options for the villagers.

Bandhaya, Halhu, and Kelende form a cluster of villages served by the Bandhaya HWC. Bandhaya, the main village, is directly connected to the block headquarters, albeit via a broken approach road, which poses accessibility challenges. Halhu village, located 3 km from the HWC, is relatively better connected with a concrete road, suggesting easier access to

healthcare services for its residents. Kelende, situated 5 km from the HWC, faces accessibility issues similar to Bandhaya's, with the added distance challenge since a broken road connects it.

Tusmu HWC

In our study, Tusmu HWC emerged as one of the better-performing centres. Located 25 km south of the Community Health Centre (CHC) Ratu, it is an area noted for its strong agricultural productivity. However, public transportation options are limited, with auto-rickshaws being available only on the weekly market days (*haat*). The CHO at Tusmu HWC was observed to be dedicated, contributing to the centre's performance.

The Tusmu village cluster, including Tusmu, Kolambii, and Upardaha, each presents distinct characteristics regarding accessibility and proximity to the local HWC. Tusmu village, which houses the HWC, is situated 5 km away from the National Highway, connected by a village road. This suggests a moderate level of accessibility for residents and those visiting the HWC from nearby areas. Kolambii, located approximately 3 km from the HWC, is linked through a broken village road, indicating potential challenges in accessing healthcare services due to the road's condition. Upardaha, closer to about 2 km from the HWC, was undergoing construction of its approach road at the time of the study, signalling improvements in access and infrastructure soon.

Lalgutwa HWC

Lalgutwa HWC, positioned 10-12 km southeast of the Community Health Centre (CHC) Ratu, benefits from a concrete road connection, indicating good accessibility. The HWC is located in Lalgutwa village, which serves as its primary service area. A high population density characterizes Lalgutwa, and most of its residences are pucca (concrete) houses.

Nayasarai HWC

The Nayasarai HWC is strategically located approximately 15 km southeast of the Ratu Community Health Centre (CHC), with the advantage of being connected by a concrete road. Situated in Nayasarai village, the HWC benefits from this well-connected, high-density population centre. The village predominantly comprises *pucca* (concrete) houses, reflecting a developed and stable living environment. Notably, Nayasarai has a significant concentration of minority population, adding to its diverse demographic profile. A majority of the households in the village have members who are wage earners working in the city.

Tundul HWC

The Tundul HWC, located 18 km southeast of the Community Health Centre (CHC) Ratu, has good connectivity with a concrete road leading to it. The village of Tundul, home to the HWC, is characterized by its minority population and several hamlets linked by village roads. This network of roads facilitates access to the HWC for residents across the village and its adjoining areas. A notable aspect of Tundul is that the majority of its households have members who are wage earners in the city.

Tiril HWC

Tiril HWC, positioned 25 km southeast of the Community Health Centre (CHC) Ratu, benefits from a reliable infrastructure connected by a concrete road. Situated in Tiril village, the HWC is located next to Ranchi, near significant landmarks like the High Court and Vidhan Sabha Bhavan, and is well-connected through good roads. Many houses in Tiril are *pucca* (concrete). Most households in the village have members who are city wage earners.

Additionally, the village of Hotwasi, though farther from the Tiril HWC, is located near one of the major markets in the area, providing its residents with easy access to essential services and amenities.

Puri, Odisha

Puri is a major city and district headquarters located 65 km from Bhubaneswar, the state capital. The population in these areas is diverse, comprising general caste, OBC, and SC, with a higher proportion of the general category estimated to be around 60-70%.

The study area is located near Puri Sea Beach, a vast urban slum in the coastal plainland. Most families' primary income sources are small-scale retail businesses, including pan shops, vegetable and seafood stalls, fast food outlets, stores selling prayer items, and occupations like auto-rickshaw driving and cycle rickshaw work. However, most of these families are low-income, with a significant portion of their earnings spent on social and religious events, family functions, and rituals. Short-duration migrations further challenge their economic situation for various reasons, often disrupting their adherence to medical treatments.

Dolabedikona(Balliapanda) UPHC

The Urban Primary Health Centre (UPHC) was initially near the Jagannath Mandir but recently relocated closer to the slum community, within 1-3 km from the habitation. This UPHC is only a few years old; it is well-equipped and maintains high standards of hygiene and resources. The Medical Officer, who has been with the UPHC since its inception, along with the ASHAs and ANM, works closely with the community. They focus on prevention, timely identification, treatment, and ensuring adherence to treatment for non-communicable diseases. The area benefits from good connectivity, with public transport and private auto and cycle rickshaws readily available.

Penthakata UPHC

Penthakata, an extensive urban slum in Puri City, Odisha, is situated 2-3 km from the city centre and close to the coastline. The community primarily relies on fishing and associated activities like wholesale and retail fish trade, dry fish business, ice factory operations for fish preservation, and net and boat repairs. This area is notably vulnerable to natural disasters such as cyclones and tidal surges, posing significant risks to life and livelihood.

The locality has decent communication facilities, with good public and private transportation options like autos, cycle rickshaws, motorcycles, and bicycles, particularly on routes connecting to Puri city. However, the internal lanes of the slum are in poor condition, hindering the movement of vehicles.

Housing in Penthakata is predominantly *semi-pucca* with asbestos roofs, and some dwellings are thatched, often in unhygienic conditions. The population density is high, with tiny *kuchha* houses of 150-200 square feet accommodating families of 4-5 members. The area's drainage system is poorly maintained, leading to mosquito breeding and the spreading of infectious diseases. Garbage disposal is another challenge due to inaccessible narrow streets, and municipal water taps are often found in unsanitary conditions.

The local Urban Primary Health Centre (UPHC) is conveniently located and well-equipped, housed in a new building with sufficient staff and facilities. The UPHC experiences a high outpatient count, supported by a punctual MO and a reliable drug supply chain.

However, the community needs help accessing public health services due to the UPHC's operating hours, which clash with their work schedules. Community demand is for decentralized Non-Communicable Disease (NCD) services through Village Health and Nutrition Days (VHNDs) and specific health camps for hypertension and diabetes. Seasonal migrations to Andhra Pradesh and Telangana disrupt treatment adherence, further complicating healthcare access and continuity.

3.2 Study Participant Profile

Age

The average age of respondents (N=1457) was 56 years. The age ranged from 52 years in Assam to 60 years in Chhattisgarh. There was an insignificant difference in mean age between male and female respondents. Out of 1457, only 21 respondents were 30 or under 30. This would correspond to the fact that respondents were acquired from the lists available at the HWCs, and the current programme focus is on the age group over 30 years.

Chart 2: Age wise distribution of study participants (N=1457)

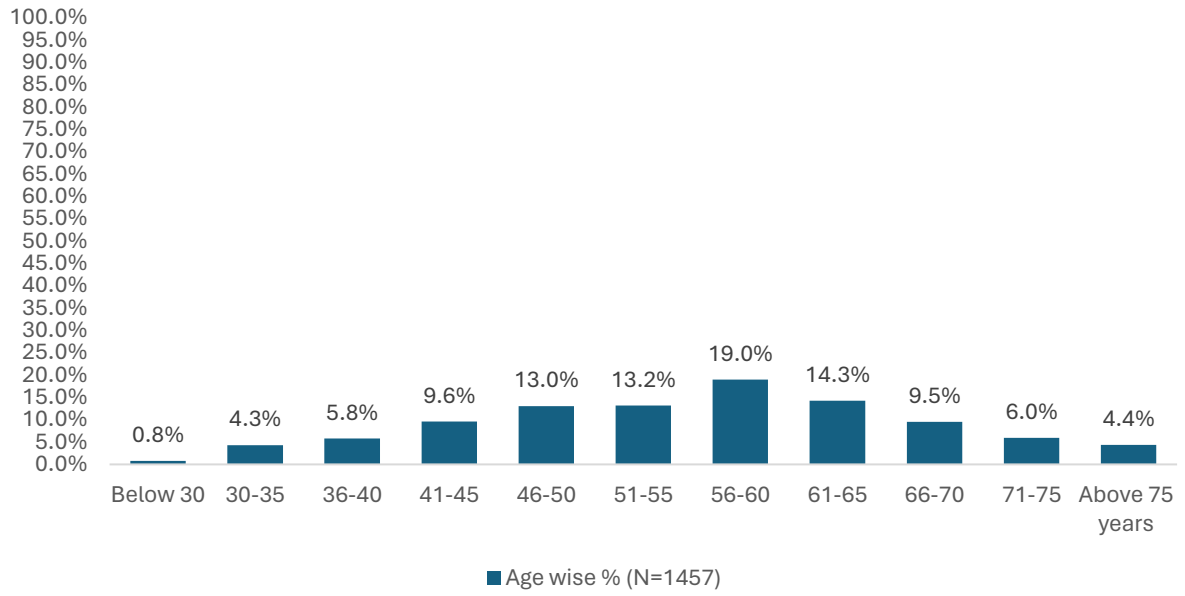


Chart 2 above shows that the participants of the study are concentrated in the age group of 46 to 65 years; the most participants (19%) were in the age group of 56-60 years. It is important to see that there is relatively equal prevalence among the younger population between 30 years and 45 years as it is among the older population of 66 years and above.

Gender

Notably, 64% of respondents were female, and 36% were male (N=1458).
This is reflective of the fact that we were mostly only able to interview patients who were available at their homes during the day. Only in a few cases were interviews conducted in workplaces; usually the agricultural fields for rural areas and marketplaces or beaches for urban areas.

Religion

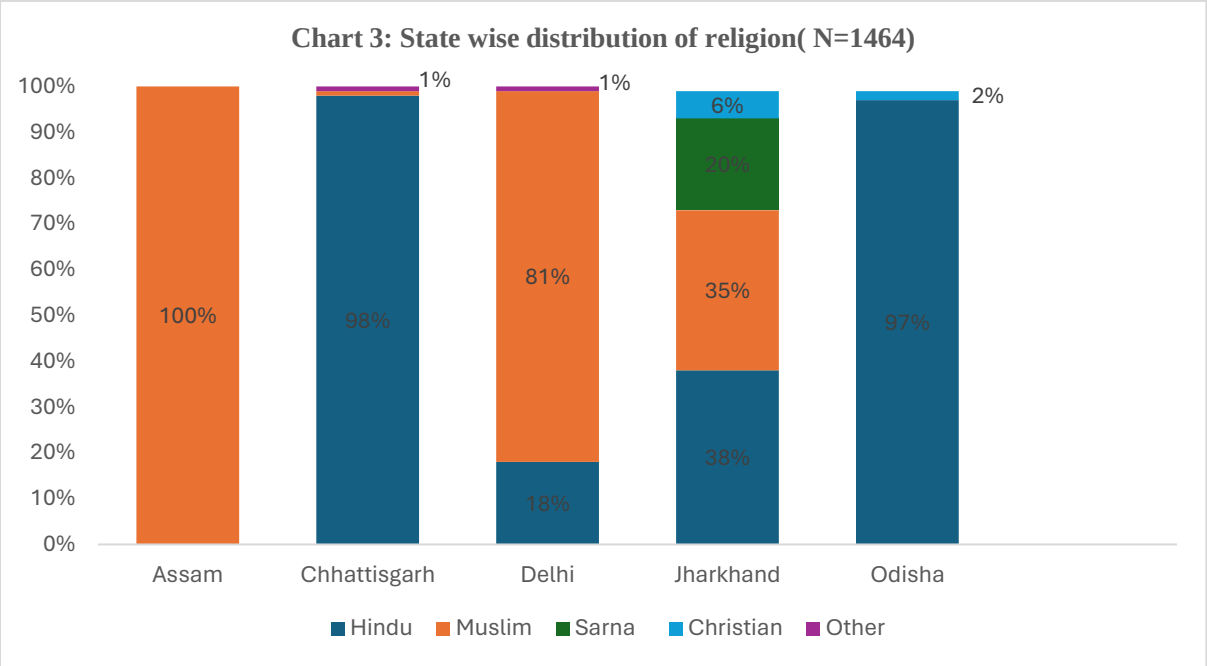
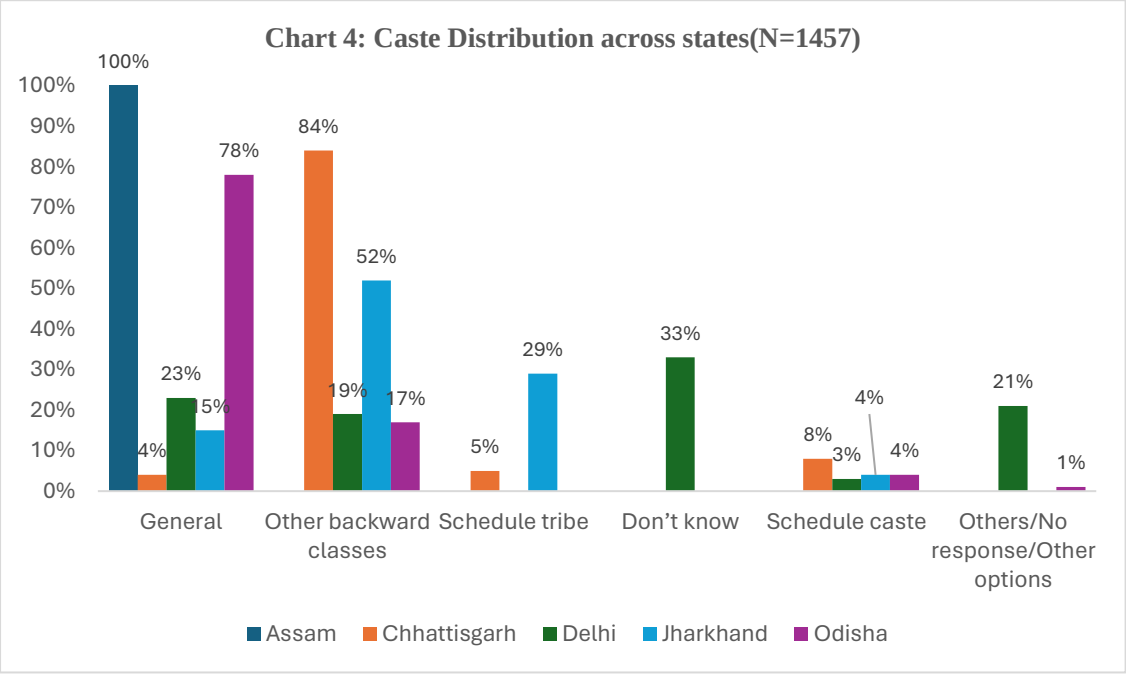


Chart 3 shows the distribution of religion across the five states. The study participants represent almost all religions which includes Hindus, Muslims, Christians, and Sarna (an indigenous religion). We have tried to cover minority communities in Assam and Delhi, Sarna and Christians in Jharkhand, with Hindus being represented as high majority in Chhattisgarh and Odisha.

Caste



The overall caste distribution across the sampled states reveals a diverse caste representation, with varying predominance of different caste groups such as backward classes in

Chhattisgarh, Jharkhand, and Delhi, a significant general caste presence in Assam, notable scheduled tribe representation in Jharkhand, and a contrast between general and scheduled castes in Odisha.

Assam appears to have a predominance of individuals from the general caste category, with notably fewer patients from backward classes and minimal representation from scheduled tribes and castes. This suggests a relatively homogeneous caste structure compared to other states in this sample.

A significant majority of respondents from backward classes characterize Chhattisgarh. compared to other states, it shows a less diverse caste distribution, with other caste categories present to a much lesser extent.

Delhi shows a mixed caste distribution, with many patients identifying as backward classes and a fair representation of the general caste. Notably, Delhi has a substantial proportion of individuals who did not identify their caste or were unaware of it.

Jharkhand had a more balanced distribution among the caste categories, with scheduled tribes being the most represented. The presence of backward and general castes, to a lesser degree, indicates a more heterogeneous caste composition.

Odisha primarily shows individuals from the general and scheduled caste categories, with few from backward classes and scheduled tribes.

Occupation

Overall the highest number of (38%) respondents were in unpaid housework. 15% were unemployed (Note that these were not mutually exclusive categories). 13% were involved in self-employed agriculture work followed by 12 % in self-employed non-agriculture work. As mentioned, the majority of the respondents were female and this distribution is undoubtedly reflective of the gender bias of the sample.

Annual Income

Table 5: Annual income across study sites

States	Less than 50,000	50,000-1,00,000	1,00,000-1,50,000	1,50,000-2,00,000	2,00,000-2,50,000	Above 2,50,000 and others	Prefer not to say	N
Assam	41%	22%	17%	13%	6%	1%	0%	**309**
Chhattisgarh	59%	31%	6%	1%	1%	1%	0%	**271**
Delhi	8%	17%	19%	5%	3%	5%	44%	**301**
Jharkhand	23%	39%	20%	11%	1%	6%	0%	**304**
Odisha	11%	27%	41%	18%	1%	1%	0%	**273**
Grand Total	**28%**	**27%**	**21%**	**10%**	**2%**	**3%**	**9%**	**1458**

Table 5 represents that out of the total participants, the maximum (28%) were in the lowest income bracket of less than Rs.50,000 in a year, followed by the second highest (27%) number of participants in the income bracket where they are earning between Rs.50,000-Rs.1,00,000 annually and the third highest (21%) in the Rs.1,00,000-Rs, 1,50,000 income per year bracket. The least percentage of participants (3%) were in the maximum income bracket of above Rs.2,50,000 annually. Chhattisgarh (59%) and Assam (41%) states had the highest

responses in ‘Rs 0- Rs 50,000’ category. While Delhi (8%) and Odisha (11%); both urban areas, had the lowest responses in this category.

Similar to the findings from the caste, majority of the participants in Delhi (44%) preferred not to share information related to their income.

Educational status

Table 6: Literacy status among study participants

States	Non literate/ Not gone to school/ Can sign his/her name only
Assam (n=308)	64%
Chhattisgarh (n=278)	60%
Delhi (n=300)	40%
Jharkhand (n=304)	63%
Odisha (n=269)	29%
Total (N=1459)	**51%**

Assam, Chhattisgarh, and Jharkhand have notably high percentages of non-literate individuals who have not attended school or can only sign their names. These states show more than half of the sampled population falling into this category.

Delhi contrasts these states, with a smaller but still significant portion of the population being in the lowest education bracket.

Odisha stands out with the lowest percentage of individuals in this category.

Considering incomes and literacy, clearly the sample adequately represents vulnerable sections that would be expected to have greater challenges with respect to treatment adherence.

Ration card

Overall, 83% of the people (N=1464) had a ration card. Chhattisgarh had the highest (98%) while Delhi stood out with only 58% (lowest among sites) of people having access to PDS.

Migration Profile

87% of the participants(N=1466) said they had always lived in the same village/ward. In this, only Delhi was an outlier where 49% said they had not always lived in the same ward. Very few numbers of all participants (28/1450) said they had stayed outside their home for more than a month in the last one year.

Insulin Dependency

Table 7: Insulin users among study participants across study sites

State	Insulin users
Assam	1
Chhattisgarh	1
Delhi	12
Jharkhand	2
Odisha	3

There were nineteen cases in the study of people who had started taking insulin or other injections. Twelve of these cases were in Delhi, which is the maximum for across the various states. For thirteen patients, further information was available; nine said they started insulin more than a year ago, and two said it had been started between six months and a year ago.

The following sections pertain to the findings specific to the status, enablers and barriers to treatment adherence. Since patient behaviour is a complex phenomenon and a net result of multiple factors, there is a degree of overlap in the sections in an attempt to provide depth and nuance to understanding the data better alongside its likely correlations, rather than in isolation. Relevant information from the qualitative methods have been included under the appropriate sections for the same purpose. Thus the data is presented and discussed as required within the same sections.

3.3 Diagnosis of disease

3.3.1 Disease-wise profile of patients

Of the total patient survey conducted, 44% were diagnosed with hypertension, 32 % were diagnosed with diabetes, whereas 23% were suffering from both hypertension and diabetes. The highest number of patients diagnosed with hypertension was in Chhattisgarh (62%) and the lowest in Odisha (23%), for diabetes the highest was in Odisha (60%) and lowest in Chhattisgarh (13%). The graph below present state wise distribution of the diseases among the participants.

Table 8: State-wise distribution of the Diabetes, Hypertension and Both the diseases

Study sites	Total	Hypertension	Diabetes	Both hypertension and diabetes	Gestational diabetes	Any others/any combination of the previous responses
Assam	309	167 (54%)	94 (30%)	48 (16%)	0 (0%)	0 (0%)
Chhattisgarh	278	172 (62%)	36 (13%)	69 (25%)	0 (0%)	1 (0%)
Delhi	303	108 (36%)	86 (28%)	106 (35%)	2 (1%)	1 (0%)
Jharkhand	303	129 (43%)	94 (31%)	71 (23%)	0 (0%)	9 (3%)
Odisha	274	64 (23%)	165 (60%)	45 (16%)	0 (0%)	0 (0%)
Grand Total	**1467**	**640 (44%)**	**475 (32)**	**339 (23%)**	**2 (0%)**	**11 (1%)**

The data shows that nine responses (3%) indicating 'others/combination disease' were from Jharkhand. Within this, four individuals, indicated that subsequent medical evaluations revealed no presence of disease, suggesting initial misdiagnoses, resolved health issues or denial or diagnosis. Furthermore, two patients reported a lack of disease disclosure from their Auxiliary Nurse Midwife (ANM), and three individuals were not engaged in any treatment regimen and perceived themselves as free from any ailments. Only a solitary case reported a comorbidity, identifying a stroke as a concurrent health condition alongside diabetes and hypertension.

These findings may suggest a reticence among patients to acknowledge their chronic disease diagnoses, which may be attributed to the long-term implications of such conditions. This apprehension potentially extends to the consumption of allopathic medications, and this came up repeatedly in qualitative narrative.

"It was found that patients hesitate to accept the diagnosis of their disease, especially given the chronic nature of the disease, and also hesitate to take allopathic medicine." (CG ASHA, CG CHO, Odisha ASHA, one respondent in Assam)

Of the responses in five states, two from Delhi were identified with gestational diabetes diagnosed 8 and 19 years ago respectively.

Table 9: Diagnosis (less than a year) of Hypertension and Diabetes

	Percentage of cases where disease diagnosed less than a year ago	**N**
Hypertension	8%	624
Diabetes	6%	459

Within the survey data, 8% of hypertension cases and 6% of diabetes cases have reported learning of their diagnosis within the past year. For those with a longer-established diagnosis—spanning one year or more—the mean duration since diagnosis is five years for hypertension (575) and 5.3 years for diabetes (430). Clearly, only a small number of patients had a very recent diagnosis. This is relevant while studying adherence which is often poor at the extremes of disease durations.

A comparative analysis across states reveals significant variance in the duration of diagnosed hypertension. Notably, the average duration in Delhi is 10.6 years (204), which markedly exceeds the average duration of three years observed in Assam (152). Similarly, for diabetes, Delhi again presents a longer average duration of 9.9 years (186), compared to the shorter average of three and a half years in Assam (84).

It is evident from the findings that a relatively minor fraction of the patient cohort has been diagnosed recently. This detail is pertinent to examining treatment adherence, which frequently exhibits suboptimal levels at the polar extremes of disease duration. The data enhances the comprehension of adherence patterns over the life course of these chronic conditions. Given the lifelong nature of diabetes and hypertension, it is imperative to understand the temporal progression and management of these diseases within the patient population.

3.3.2 Facility where first diagnosis took place

Table 10: Facility where first diagnosis took place

Health facility	Assam	Chhattisgarh	Delhi	Jharkhand	Odisha	Grand Total
Health and wellness centre	304 (98%)	112 (40%)	NA	41 (14%)	1 (0%)	458 (31%)
Private hospital	4 (1%)	32 (12%)	33 (11%)	64 (22%)	59 (22%)	192 (13%)
Urban primary health centre	NA	5 (2%)	1 (0%)	3 (1%)	164 (60%)	173 (12%)
Private unregistered clinic	-	87 (31%)	67 (22%)	-	13 (5%)	167 (11%)
District Hospital	-	13 (5%)	27 (9%)	13 (4%)	34 (13%)	87 (6%)
Government Dispensary	NA	NA	75 (25%)	NA	NA	75 (5%)
Others	1 (1%)	29 (10%)	99 (33%)	174 (59%)	1 (0%)	304 (21%)
Grand Total	309	278	302	295	272	1456

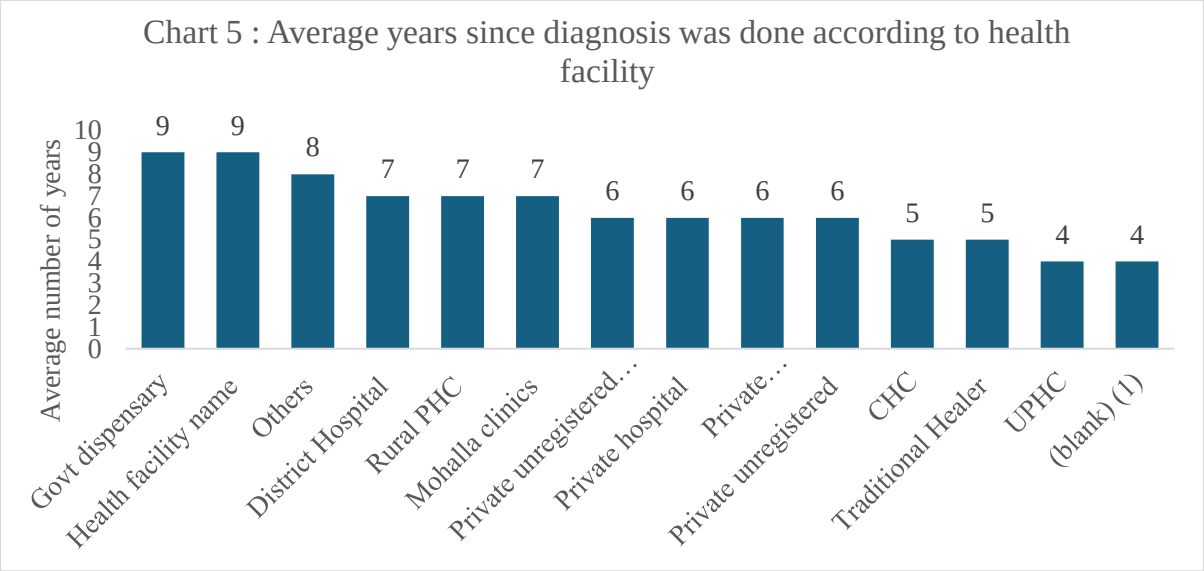
Diagnosis in public sector- Highest proportions of patients in all contexts (54%) including Jharkhand (19%) had found out about their disease in the primary public health system overall. In Assam 98% found out about their diseases in HWC. In Odisha; an urban area, 60% patients had found out about the disease in the UPHC. Therefore, Assam, followed by Odisha did well in terms of diagnosis/identification at primary level. Notably another 13 % in Odisha were diagnosed at a District Hospital. For Delhi too, the maximum diagnosis was across the public health system, though relatively more had been diagnosed at the tertiary care level (10% in a tertiary hospital like LNJP, included under 'others') as compared to other states. it included 25% patients finding about it in government dispensaries and district hospital contributed to 9% of the diagnosis.. The diagnosis at higher facilities may or may not have been opportunistic to presenting with other major diseases. In Jharkhand, 14% of the patients were diagnosed in HWC whereas 4% in district hospital and another 8% had been diagnosed in 'NCD camp at AWC' (N=295) held by the CHO.

The quantitative data shows that the maximum initial diagnosis in Assam was done at the HWC level. The qualitative data further suggests that sometimes the patients were hesitant to only rely on the HWC reports for their diagnosis and sought further confirmation of their disease from other healthcare providers or systems. As a group of ASHAs in Assam shared- *"Some patients, upon hearing that they have either been diagnosed with hypertension, diabetes, or both, do not accept the report; as a result, they seek a second opinion at the medical college or at one of the private clinics."* (Assam ASHA FGD 1).

Diagnosis in private sector- In Jharkhand, 41% of patients had found about their disease in the formal or informal private sector (which was reported as 'other') with very low coverages at the primary facilities of the HWCs. This was followed by Chhattisgarh (12% in private hospital and 31% in private unregistered clinic) patients being diagnosed in the private healthcare facilities. In Odisha and Delhi too, many had found about their disease in private sector. Assam stood out with only 1% learning about their disease in a private hospital.

In Jharkhand, three patients responded that they were diagnosed "At AWC during advertisement of Ayurvedic Medicine by private vendor".

The high reliance on private sector for initial diagnosis in Jharkhand as seen from the data above is supported by the what the ASHAs in Jharkhand said " *patients did not have faith in the diagnosis done at the primary health centre level"* attributing the decision to faith. However, data subsequently suggests that health seeking behaviour was often conditioned by access as well.



Government dispensaries in Delhi had the highest average years since any diagnosis, at nine years. Longer average times since diagnosis for Delhi were most likely to be reflective of the large number of tertiary hospitals and private hospitals with a very small number reported from Mohalla clinics as the source of first diagnosis.

'Others' and district hospitals have an average of eight and seven years since diagnosis respectively. Private unregistered clinics and private hospitals had an average of six years since diagnosis for a substantial number of patients.

UPHCs had an average of four years since diagnosis, indicating that they had only recently begun to diagnose such conditions having been established in the area recently.

HWCs had the shortest average duration since diagnosis at three years for attending patients, which could reflect the recent expansion of such centres. Rural PHCs, Mohalla Clinics, and Pharmacies**,** had an average of six to seven years since diagnosis but represent a small number of patients, suggesting that while they had served as points of diagnosis for some time, they did so for fewer patients.

The above analysis suggests that the HWCs have been successful in creating a large pool of fairly recently diagnosed NCD patients who would either have gone undiagnosed or would have been diagnosed in the private sector at some future date if the HWCs was not operationalising the NCD programme.

In the urban areas the average time since diagnosis was more than the rural sites albeit with Delhi being double that of Odisha at the primary healthcare level. In Odisha even though at the primary level(UPHC) the average years was four years, some patients were diagnosed at the district hospital where the average years since diagnosis would be higher. The Delhi site being very different from the urban slum settlement in Puri, once can see the role of the preestablished multitude of health systems including tertiary hospitals, government

dispensaries (which have been providing Diabetes and Hypertension services for some time) and private providers, and Mohalla clinics.

However, Jharkhand is the more significant case of most patients reporting first diagnosis in the private sector despite being eligible for the HWC-run NCD programme also leading to slightly higher average time since diagnosis as compared to Assam, since the pre-existing private sector seems to be more operational than the relatively recent HWCs. This exception continues to stand out in the entire analysis that seems to suggest that the public health system is functioning poorly in Jharkhand. To illustrate this point further, for Assam and Chhattisgarh diseases diagnosed in the HWCs specifically had an average of three years since diagnosis. However, in Jharkhand HWCs average years since diagnosis for HWC was *two* years, possibly signifying a delay in rolling out the programme.

3.4 Information given to patients when the condition was diagnosed.

It is important for patients to understand that they are diagnosed with lifetime diseases and initial counselling has to be done to ensure future treatment adherence.

At the time of diagnosis of the condition, 22% of patients were not told anything about how long they would be needing the treatment. The highest proportion for this was in Delhi (62%) while the lowest was in Assam (2%).

A CHO in Chhattisgarh said, *"that patients understand but they panic because they are told that they have to take medicine lifelong and what are the complications that could occur. In such cases, patient have to be explained/counselled well by healthcare providers."*

The information that the patients were given with regard to their disease included monitoring of their blood pressure and sugar levels as well as possible side effects that they may face. Majority of the patients (77%) were informed that their blood pressure and blood sugar levels would need regular monitoring, though fewer patients (36%) were informed that their medication or its dosage may need to be changed during the course of the disease. Majority of the patients (71%) said that the healthcare provider answered their questions or clarified their doubts about the disease.

The information given with regard to side-effects varied across states, in Assam most (96%) patients were asked to contact CHO in case they faced side-effects. In Odisha majority (75%) patients were asked to refer to the ASHA and 46% in Jharkhand were told to visit the nearest HWC in case they faced any side-effects. Majority of the patients in Chhattisgarh and Delhi were not given any information regarding side-effects, 85% and 84% respectively. In this context it becomes interesting to note how one CHO in Chhattisgarh mentioned patients felt that it is not good to take medication due to side effects, "(*For allopathic medicine), people think that there are side effects and too much medicine is not good"* (CHO CG 1). Hence when the patients are not clearly informed about side-effects and medicine use, the myths and lack of understanding persists among the people in the community.

3.5 Information given to patients on medication, diet, physical activity, substance abuse etc. at the time of diagnosis.

Table 11: Percentage of patients who were given information on different aspects of Treatment Adherence at the time of diagnosis (%)

What all were you told about how you can manage this disease	Assam	Chhattisgarh	Delhi	Jharkhand	Odisha	Grand Total
To take medication regularly / take medication	92%	92%	68%	88%	73%	80%
To make changes in food habits and diet	48%	72%	53%	87%	49%	62%
To regularly get vitals (BP and blood glucose) monitored	61%	74%	35%	47%	13%	46%
To make lifestyle changes (exercises etc)	33%	21%	10%	36%	49%	29%
To be alert to possible side effects	5%	18%	4%	3%	50%	15%
To be more alert to other health issues that may arise (like notice foot ulcers, visit doctor for other infections quickly)	1%	1%	2%	26%	37%	13%
To refrain from use of substances (alcohol, tobacco etc)	8%	27%	3%	4%	9%	10%
Not been told any of the above	0	5%	4%	2%	0	2%
Any others	0	1%	5%	1%	0	2%
N	**309**	**278**	**301**	**294**	**270**	**1452**

At the time of diagnosis, most of the patients were given information regarding taking medicines and getting regular tests done. This was followed by information on diet changes (62%), information on physical exercise (29%) and information on substance abuse (10%). For the indicator on substance abuse, Assam did not fare as well considering that most data suggest it is a front-runner with respect to the NCD programme in this study.

The data illustrates that while there is a high level of consistency in advising patients to take their medication regularly, there is considerable variability in the communication of other management strategies across the states. The percentages are lower for lifestyle modifications, awareness of side effects, and alertness to other health issues. However, there are significant regional differences. Across the board, diet related advice seems to be generally given with progressively lower percentages of information on exercise and substance abuse. Notably, Odisha, with its primary treatment via UPHC does better on information related to complications and side effects.

3.6 Facility approached for current treatment

Table 12: Facility visited for treatment of disease (%)

State	Assam	Chhattisgarh	Delhi	Jharkhand	Odisha	Total
Health and wellness centre	306 (99%)	236 (85%)	0	65 (22%)	3 (1%)	610 (42%)
Urban primary health centre	0	3 (1%)	0	4 (1%)	210 (77%)	217 (15%)
Government dispensaries	0	0	146 (48%)	0	0	146 (10%)
Private MBBS doctor	1 (0)	4 (1%)	19 (6%)	72 (24%)	51 (19%)	147 (10%)
Others	2 (1%)	7 (3%)	6 (2%)	20 (7%)	0	35 (2%)
Private unregistered clinic	0	12 (4%)	21 (7%)	17 (6%)	2 (1%)	52 (4%)
Private pharmacy/Medical shop	0	11 (4%)	25 (8%)	25 (8%)	0	61 (4%)
Mohalla clinic	0	0	15 (5%)	0	0	15 (1%)
District Hospital	0	1 (0%)	6 (2%)	2 (1%)	8 (3%)	17 (1%)
Other responses/combination of responses	0	4 (1%)	45 (15%)	60 (21%)	0	109 (7%)
Not taking any treatment	0	0	0	31 (10%)	0	31 (2%)
Tertiary hospitals	0	0	20 (7%)	0	0	20 (1%)
Total	**309**	**278**	**303**	**296**	**274**	**1460**

The table above presents the data related to the kind of health systems being utilised in these different contexts. Overall, 70% of the patients were taking treatment in primary public health facilities. The state wise data shows- Assam (99%) and Chhattisgarh (85%) exhibited care by the HWC, Odisha (77%) by the UPHC, and Delhi exhibited care by the government dispensaries (48%) and mohalla clinics (5%) and Jharkhand largely from the private sector despite being a rural area.

Patients, 38% in Jharkhand, 21% in Delhi and 20% in Odisha were taking treatment from formal or informal private sector. Delhi and Jharkhand had high private sector responses under "all other responses/combination of other responses" too. The only state where patients were taking treatment from a tertiary hospital was Delhi and this was high at 7%.

Thus, the data shows distinct preferences for using certain healthcare facilities for treatment in different states with respect to our sample. Assam and Chhattisgarh primarily depended on HWC, whereas Odisha leaned heavily on Urban Primary Health Centres. Delhi exhibited a more diversified utilization of healthcare facilities, with many patients using government

dispensaries, private healthcare provider, and other facilities. Jharkhand greatly relied on private healthcare providers, including MBBS doctors and clinics.

Comparing the proportion of patients first diagnosed at HWC/ UPHC/dispensary (54% Table 10) against those taking medications from the same (70%) it can be seen that even if patients were not diagnosed at HWC/ UPHC/dispensary, larger number were currently taking treatment in these facilities.

To illustrate, whereas diagnosis was high in the private sector for Chhattisgarh (43%), fewer (9%) were taking treatment from the private sector at present. A high number of patients (85%) were getting treatment from HWC.

For Odisha 13 % of patients were diagnosed in DH but much less were either taking treatment or medicine from DH and the same for Delhi; a fact which in itself does not necessarily cause concern if they had shifted to a primary facility for continuity of care.

Thus, patients are navigating a combination of public and private healthcare facilities fluidly, tailoring their choices to meet their individual healthcare needs. The underlying reasons and contributing factors for this health-seeking behaviour, particularly related to treatment adherence, are further elaborated upon in the following sections.

3.7 Health facility visited for follow up including diagnostics.

Table 13: Facility being visited for follow-up (%)

State	Assam	Chhattisgarh	Delhi	Jharkhand	Odisha
HWC	89	85	0	33	0
MO at health and wellness centre/Urban primary health centre	7	2	0	7	74
Government Dispensaries MO/Mohalla clinic	0	0	48	0	0
Do not go anywhere	0	4	27	8	1
Private MBBS doctor	0	0	4	17	19
Private unregistered medical practitioner	0	3	4	0	0
HWC and private clinic	0	0	0	15	0
Private pharmacist/ Medical shop	0	0	0	5	0
Others	2	5	15	14	6
Total (N)	**309**	**277**	**293**	**254**	**268**

Follow-up visits in the public sector- 97% patients in Assam and 87% patients in Chhattisgarh were going to the HWC for their follow-up visit. 74% patients in Odisha were going to the UPHC and 48% patients in Delhi were going to the dispensary or Mohalla clinic. Only 33% patients in Jharkhand were going to the CHO. However, there were another 15% patients in Jharkhand who responded “HWC and private clinic” (counted under others) which implied that they were taking treatment from both.

Follow-up visits in the private sector- 22% patients in Jharkhand, 19 % patients in Odisha, and 8% patients in Delhi went to the private sector for their follow-up. Notably, a high 27% of patients in Delhi said they do not go anywhere for follow-up.

Frequency and place of BP testing

In Assam and Chhattisgarh, a substantial majority of respondents, 93% and 84%, respectively, reported that their blood pressure is monitored at least once a month. Furthermore, in these states, the monitoring predominantly takes place in HWC, as indicated by 95% of respondents in Assam and 82% in Chhattisgarh. In Chhattisgarh, 8% of the participants mentioned that their blood pressure monitoring occurs at home, which, as discerned from the qualitative findings, is often facilitated by ASHA workers. In Odisha, 60% of the population gets monthly blood pressure tests done, with 73% conducted at Urban Primary Health Centres (UPHC).

Interestingly, even in Jharkhand, 64% of patients got their blood pressure test done monthly and 58% had it done at the HWC. This is a much higher percentage for Jharkhand compared to those who said they were taking medicines or going to the government sector for follow-up. This relates to poor medicine availability in HWC but better availability of blood pressure and diabetes tests, as learnt from the study teams. In addition, there were also some old cases or people who were taking medicines different from the government sector and preferred to take those instead of government ones even if they continued to get their blood pressure checked at HWC. This also held true for cases where people were going to bigger hospitals for major diseases and preferred to take their medicines from that hospital or health provider.

Delhi stood out for both these indicators. Only 30% had their blood pressure tests done monthly. 34% said they got it from Mohalla Clinic/Govt dispensaries, and 14% said it was not taken routinely at all. 22% in Delhi said they did it at home and it was later shared by the state study team that people commonly had blood pressure machines and were doing it at home on their own.

Table 14: Frequency of monitoring the blood pressure

	Monthly	the medication from the	Is not taken	Others	Every two months	Every 3 months	0	Twice in a month	Twice a year	Once a year	N
Assam	93%	1%	0%	0%	4%	2%	0%	0%	0%	0%	214
Chhattisgarh	84%	8%	4%	0%	2%	0%	0%	2%	0%	0%	241
Delhi	30%	13%	18%	24%	7%	2%	0%	4%	1%	0%	212
Jharkhand	64%	2%	2%	0%	7%	9%	12%	0%	1%	2%	214
Odisha	60%	28%	0%	0%	2%	10%	0%	0%	0%	0%	103
Grand Total	**68%**	**8%**	**5%**	**5%**	**4%**	**4%**	**3%**	**1%**	**1%**	**1%**	**984**

Table 15: Institutions where the blood pressure is monitored

	HWC	UPHC	Home	Private clinic/hospital	Government dispensaries	Is not taken	Others/ Combination of responses	N
Assam	95%	0%	2%	0%	0%	0%	3%	279
Chhattisgarh	81%	1%	8%	2%	0%	5%	4%	243
Delhi	0%	0%	22%	17%	34%	14%	12%	209
Jharkhand	57%	1%	7%	13%	0%	0%	22%	222
Odisha	1%	72%	0%	21%	0%	2%	0%	121
Grand Total	55%	8%	8%	9%	6%	4%	10%	**1074**

ASHA and BP machine in CG -In Chhattisgarh *ASHAs* were provided with BP machines for measuring blood pressure of the patients at the community level. This has increased the access among the patients, which has been much appreciated. However, as mentioned by the *ASHAs* "*the BP machine stops working and they have to spend money from their own pocket to get it repaired*" (ASHA FGD 1 & 2).

Frequency and place of blood sugar testing

Overall, 66% patients said their blood sugar test was done monthly. This ranged from 39% in Delhi to 96% in Assam.

Most (98%) patients in Assam said their blood sugar test was done at the HWC, 81% patients in Odisha said it was done in UPHC, and 77% patients in Chhattisgarh and 58% in Jharkhand said it was done in HWC. 40% patients in Delhi got it from the dispensary/Mohalla clinic and 22% said they did it at home. Once again, in Jharkhand where most people took their medicines from the private sector and even went for follow-up to the private sector, they responded positively to getting blood pressure tests done in a public facility. This reinforces the emerging findings that people use public health services variably, partially or wholly based on their circumstances as well as the quality of services available at various centres.

Table 16: Frequency of blood sugar testing

Frequency	Assam (142)	Chhattisgarh (106)	Delhi (194)	Jharkhand (161)	Odisha (206)	Grand Total (809)
Monthly	96%	77%	39%	78%	55%	**66%**
Whenever I go to take the medication from the health facility	4%	4%	7%	1%	21%	**8%**
Every 3 months	0%	4%	7%	5%	18%	**8%**
Every two months	1%	1%	11%	6%	4%	**5%**
Twice a year	0%	0%	2%	2%	0%	**1%**
Once a year	0%	0%	0%	1%	1%	**0%**
Is not taken	0%	14%	13%	3%	0%	**6%**
Others	0%	0%	22%	1%	0%	**5%**

Table 17: Place of blood sugar testing

	Assam (142)	Chhattisgarh (107)	Delhi (188)	Jharkhand (153)	Odisha (201)	Grand Total (791)
Health and wellness centre (HWC)	98%	77%	0%	58%	0%	39%
UPHC	0%	0%	0%	0%	81%	21%
Government dispensaries/Mohalla Clinic	0%	0%	40%	3%	1%	9%
Home	2%	1%	22%	2%	0%	6%
Private clinic	0%	5%	12%	7%	4%	6%
Private hospital	0%	0%	2%	3%	12%	4%
Is not taken	0%	12%	8%	1%	0%	4%
Others/ Combination of responses	0%	6%	15%	26%	1%	11%

3.8 Availability of diagnostic services at the health facilities

Sugar strips for glucometers, blood pressure (BP) apparatus, and haemoglobin (Hb) tests were consistently available in all HWCs across the five states.

Highlighting a few exceptions; the CHO of Rangakathera HWC in Chhattisgarh (among the less well-performing of the three HWCs in the state) reported challenges with the availability of sugar strips. For instance, while Bagherra HWC had 300 sugar strips and Singhola HWC had 200, Rangakathera HWC only had 50, despite serving a similar population/patient base.

As a proxy for basic diagnostics, in terms of Hb testing across the states, DGD Ajmeri Gate lacked Hb test availability. The Delhi state rep 1 shared that in Delhi they have outsourced the lab services to Metropolis, SRL diagnostics, etc. They have a person called ‘runner’, who is from the outsourced lab and who is supposed to take the sample for testing at the lab like LFT, KFT, lipid profile, blood sugar for fasting blood sugar test, random blood sugar test, glucose tolerance test, HBA1C, etc. Upon enquiring based on field observations as to why some of the basic tests were also unavailable at the dispensaries, he simply said the MOs and other staff were ‘lying’.

At HWC Rangakathera in Chhattisgarh, there was an issue with the Hb meter being broken and sent for repair the previous week, leading the staff to use Sahil’s method for Hb testing.

The Dolabedikona UPHC in Odisha had all the tests available at the centre, including blood pressure, blood sugar and Hb test. There was a designated room for doing the tests. It was ensured that each time a diabetes or hypertension patient visited the facility, their tests were recorded and entered in a register.

3.9 Adherence to taking medicine in the previous one week

A one-week recall period was used to examine if patients were taking their medication regularly.

Table 18: Missed medication in the week prior to the interview

State	Don't remember (for one or more days)	Missed all 7 days/Did not take	Missed 6 days	Missed 5 days	Missed 4 days	Missed 3 days	Missed 2 days	Missed 1 day	Did not miss any day	N
Assam	3 (1%)	11 (4%)	0 (0%)	5 (2%)	12(4 %)	13 (4%)	7 (2%)	13 (4%)	242 (79%)	306
Chhattisgarh	4 (1%)	16 (6%)	0 (0%)	2 (1%)	8 (3%)	10 (4%)	5 (2%)	7 (3%)	215 (81%)	267
Delhi	9 (3%)	4 (1%)	0 (0%)	4 (1%)	4 (1%)	13 (4%)	19 (7%)	19 (7%)	220 (75%)	292
Jharkhand	0 (0%)	29 (12%)	1 (0%)	1 (0%)	6 (2%)	1 (0%)	2 (1%)	3 (1%)	208 (83%)	251
Odisha	0 (0%)	1 (0%)	0 (0%)	0 (0%)	1 (0%)	4 (2%)	19 (7%)	8 (3%)	224 (87%)	257
Total	**16 (1%)**	**61 (4%)**	**1 (0%)**	**12 (1%)**	**31 (2%)**	**41 (3%)**	**52 (4%)**	**50 (4%)**	**1109 (81%)**	**1373**

Majority (81%) of the patients had taken medicine throughout the week prior to when the interview was conducted. 4 % had missed it/did not take it on all seven days. 1% responded 'Don't remember' for at least one of the seven days in that week.

The state-wise data showed that patients in Odisha had better treatment adherence to medicine among all states, where 87% patients did not miss medicine for any day in the week prior to the interview. Jharkhand stood out where 12% had missed or did not take their medication as opposed to 4% average.

Disaggregating the data by gender, 80% and 81% women and men respectively did not miss taking medicine in last seven days whereas 4% of both men and women missed taking it for all the previous seven days. Thus there does not seem to be a difference between men and women for the actual practice of treatment adherence based on this finding.

Of the patients who had missed their medicines in the last seven days for least one day, 39% said that they simply forgot to take medication. Apart from this, patients shared the reasons for not being able to take their medication in an open-ended question and these are detailed below.

Reasons for not adhering to treatment plan for medication in the last 7 days

One main reason cited by patients for not being able to take medication was the unavailability of medicines in public health centre. For example, one patient in Jharkhand skipped taking medicine to ration its use. Another patient in Chhattisgarh used to get 10 days worth of Glimepiride and 30 days' worth of metformin from the CHO (even though both were to be taken every day). In such a situation the patient consumed medicine based on the availability - (Glimepiride at an interval of 3 days and metformin was consumed daily). Sometimes due to unavailability of medicines, many patients had shifted the treatment from allopathic to ayurveda. The issue of access to medicines comes up strongly as a factor for treatment

adherence throughout the study and has therefore been discussed in greater detail in a subsequent section.

Many patients had stopped taking medicines because their symptoms had disappeared. Other patients were either not taking medicines or skipping medicines 'on their own'. A few of them reported that their family members had told them to not have medicine daily. Other responses for not following their treatment plan were related to side effects- for example, patients felt that '*medicine created weakness or heat in the body'* so patients would skip their medicines in summers or not take the medicines every day considering it to be harmful for them. Lack of access to healthcare provider on what to do in case patients faced side-effects also affected adherence, For example, one patient said he *'attempted to contact the HWC with respect to side effects but gave up as both the time HWC was closed.*' One patient in Delhi said *"bahut ho gaya dawa aab nahi khana hai"* translated as "this is enough, now I don't want to eat medicine anymore") and similar statements were echoed by many patients across the study.

Sometimes doctors told patients to adjust medication according to their symptoms, for instance five were told by the doctors that if the symptoms are not much then the medicines could be taken at an interval of 1-2 days.

A few other patients said that they took medicines only when they felt sick. Such reasons, that people took medicine on their own based on how they were feeling and also that a person should not be eating medicine everyday emerged prominently in qualitative information from Chhattisgarh patients.

Regarding people skipping their medicines as long as their BP or sugar levels were normal, one of the patients from Chhattisgarh said- **"***Apne man se dawai khate hain"* translated as *"I eat medicine as per my will"*. The study team in Chhattisgarh observed that patients sometimes took medicine on alternate days or in two-four days interval or sometime people would take half a tablet. One reason people skipped medicines was because they felt nauseous. An ASHA shared patient responses- *"Chakkara aata hai, khana nahi kha raha hai, garmi lag raha hai (feel dizzy, unable to eat food, feel hot) " (*CG ASHA*).*

3.10 Access to medicines

The analysis presented below is based on the access to medicine at public and private facilities both.

Table 19: Facility from where medication is being received at present (N)

State	Assam	Chhattisgarh	Delhi	Jharkhand	Odisha	Grand Total
Health and wellness centre /Urban primary health centre	307 (99.3%)	236 (84.9%)	-	64 (21.8%)	204 (75.3%)	811 (55.9%)
Private pharmacy/Medical shop	1 (0.32%)	20 (7.2%)	65 (21.6%)	131 (45%)	18 (6.7%)	235 (16.2%)
Government Dispensaries	-	-	145 (48.3%)	-	1 (0.4%)	146 (10.1%)
Private hospital	-	3 (1.0%)	16 (5.3%)	10 (3.4%)	40 (14.7%)	69 (4.8%)
Other	-	11	32	77	1	121

		(4.0%)	(10.7%)	(26.2%)	(0.4%)	(8.3%)
Mohalla Clinic	-	-	15 (5%)	-	-	15 (1%)
District hospital	-	1 (0.35%)	4 (1.3%)	1 (0.3%)	6 (2.2%)	12 (0.8%)
Unregistered medical practitioner	-	6 (2.15%)	9 (3%)	2 (0.6%)	-	17 (1.2%)
All Combination of previous responses	1 (0.32%)	1 (0.35%)	14 (4.6%)	8 (2.7%)	1 (0.3%)	25 (1.7%)
Total	**309**	**278**	**300**	**293**	**271**	**1451**

Overall, in the 4 states (excluding Delhi) which had HWC and UPHC, 70% of respondents were taking medication from HWC/UPHC with Jharkhand faring poorly among these 4 states.

In terms of state comparison, HWCs were the major source of medicines in Assam and Chhattisgarh, the UPHC in Odisha, and dispensaries and mohalla clinics in Delhi (though less in proportion than the former 3 states), but patients in Jharkhand accessed medicines largely from the private sector despite being a rural area.

Significantly, 14% in Jharkhand were not taking any treatment and 10% in Delhi (counted under 'Others') were taking medicine (exclusively or in combination with other facilities) from tertiary level hospitals like LNJP, Lady Hardinge, Pant hospital etc. Jharkhand (49%). Delhi (30%) showed high dependence on the private health sector for getting their medication. While 22% patients in Odisha were taking medicine from the formal or informal private sector.

Table 20: Availability of medicines at the health centres being routinely used.

	Always available	**Mostly available (75% of the time)**	**Other**	**vailable 50% of the time**	**Rarely available (less than 50%)**	**NA**	**N**
Assam	71%	29%	0%	0%	0%	0%	**308**
Chhattisgarh	89%	1%	8%	1%	1%	0%	**277**
Delhi	82%	12%	3%	2%	0%	0%	**299**
Jharkhand	50%	19%	26%	2%	0%	1%	**238**
Odisha	43%	43%	1%	12%	2%	0%	**265**
Grand Total	**68%**	**21%**	**7%**	**3%**	**1%**	**0%**	**1387**

Of the patients visiting the public health facility to get medicine, data reveals that 68% reported that the medicine was always available with 95% finding it available more than 75% of the time. On comparing the overall data for access to medicines through public sources in different contexts, it was found that in rural context, Chhattisgarh (96%) had highest access to medicines at all times when patients went to get it, compared to Assam (71%) and Jharkhand (46%), where as in urban setting Delhi (76%) had a better access compared to Odisha (31%). Access to medicines in both public and private facilities remained an issue in Jharkhand but not in an urban area of Delhi with 50% and 82% having access overall respectively. Access to medicine in public and private combined was low in Odisha (43%).

As discussed in section 2.2, considering the exemplary performance of Piazbari HWC a theoretical sample of Khankhowa HWC as a more challenged area, had also been included for comparison. Comparing these better and worse performing areas in Assam, 35% of respondents in Khankhowasaid the medicines were always available as against 80% in Piazbari.

Table 21: Availability of medicines in two HWCs in Assam

	Always available	Mostly available (75% of the time)	Available 50% of the time	N
Khankhowa	35.42%	62.50%	2.08%	48
Piazbari	80.49%	19.51%	0.00%	205
Grand Total	**71.94%**	**27.67%**	**0.40%**	**253**

In terms of how frequently medicines were received from and dispensed in govt facilities, 93% said they received their medicines once a month. A slight deviation among states was for Delhi where 13 out of 159 patients said they got their medications 'once in 15 days' and 20 out of 159 patients said 'weekly'.

Overall, data suggested that access to medicines from public facilities seemed quite fair in the contexts where the facilities existed and were functional. However much greater nuance was provided by the qualitative data on the influence of shortages of drugs on treatment adherence.

The data reveals a significant variation in the reliance on public versus private healthcare facilities for medication across the states. The differences can also reflect the urban-rural divide in healthcare access. For example, with its more urban setting, Delhi has a broader range of facilities, including private pharmacies, hospitals, and specialized clinics like Mohalla Clinics. Assam, Chhattisgarh, and Odisha strongly preferred public healthcare facilities, whereas Jharkhand and Delhi demonstrated a higher reliance on private sources.

3.11 Availability of medicines at the health facility as reported by the public health systems

The availability of medicines was generally marked by inconsistency, though findings suggested that healthcare facilities in various states received requested supplies to a large extent. On the whole, while it was clear that no patients were being turned away for a total lack of medicines, many did not receive the planned supply for a full month, leading to issues of treatment adherence and this was not related by patients alone; but also from the health system.

In Jharkhand, the availability of medicines by the HWC was particularly concerning, with half of the HWCs reporting no distribution of medicines for hypertension and diabetes in the given month. Additionally, one DGD mentioned not receiving metformin for the past six months, which is a significant finding. In Chhattisgarh, patient interactions revealed a prominent issue with the

Discussions with patients revealed that the medicine availability in dispensary/HWC in Delhi and Odisha is inadequate in terms of not being given full months of medicine. This is a problem for patients as they have to go more than once a month to replenish their medication which is a burden for them.

limited variety and brands of medicines available in HWCs, leading many patients to seek medication from the private sector.

In contrast, the Piazbari HWC in Assam stood out, across all the sites surveyed due to its extensive range of available medicines.

Furthermore, the study found that none of the HWCs or DGDs surveyed were supplying or distributing insulin though one DGD in Delhi had attempted to indent some insulin.

Assam

In the state, the four HWCs predominantly stocked three types of medication: Amlodipine (either 2.5 or 5 mg), Metformin, and Glimepiride. Additionally, Atenolol was available in three of these HWCs.

The Piazbari HWC, in particular, demonstrated an exemplary supply of medicines, having received its orders as requested. This centre boasted a diverse array of medications, including Telmisartan, Glimepiride (1 mg), Enalapril, and Losartan. Notably, drugs such as Enalapril and Losartan, which were available at the Piazbari HWC, were not found in the other three HWCs within the state.

Chhattisgarh

In three of the HWCs, the supplied medications included Amlodipine (5 mg), Atenolol, Glimepiride, Metformin, and Enalapril. However, Amlodipine at 2.5 mg was not supplied during the study period. Generally, the medicine supply matched the indents.

While two Community Health Officers (CHOs) were relatively content with the medicine supplies, the CHO from Rangakathera expressed dissatisfaction, citing insufficient quantities and discrepancies between the supply received and the indents. This issue had been persisting at his HWC for 3-5 years. For instance, he had only received one-fifth of the requested amount of Amlodipine in the previous month. At the time of the study, the stock levels of this HWC were also noticeably lower compared to the other two HWCs.

The CHOs also pointed out that they have never received the three-month buffer stock of medicines outlined in the guidelines.

However, the availability of medicine for the full month was not related to be a problem except in one of the three HWCs where the state study team observed that the medicine issues and in general poorer services were due to poor motivation of the individual CHO.

During one of the interviews with a CHO in Chhattisgarh, a patient who worked as a labourer came from a village that was 6 km away. His BP was under control and his sugar level was slightly increased. He was given only 10 days of medicine (Met 500 mg, Amlo 5 mg). He requested medicines for one month but the CHO didn't give them as the medicines were short in supply.

Under another HWC in Chhattisgarh, one case was found where the diabetes respondent shared that she was given metformin for 30 days but Glimepiride for 10 days only. So, she was taking Glimepiride once in 3 days so her medicines last for the month.

Delhi

The medicine supply in the DGDs was satisfactory, offering a broad selection including Amlodipine, Enalapril, Telmisartan, Hydrochlorothiazide, Glimepiride, and Glibenclamide. These medications were supplied according to the indents made by the dispensaries.

However, there were some issues noted in specific dispensaries. For instance, DGD Ajmeri Gate had indented ten vials of insulin, but these were not supplied. Additionally, in DGD Gali Samosan, it was observed that Metformin had been unavailable for the past six months.

R2 Delhi said medicines are available at the dispensary but they are given only for 15 days.

R3 Delhi shared that she has to fight with the doctor in the dispensary to receive one month of medicine and not 15 days.

Another said- ***"Ek baar jao to daava puri nahi milti" (I never get the required dose of medicine from the dispensary) (R4 Delhi).***

Jharkhand

Data on medicine availability was gathered from six HWCs.

The state exhibited a varied pattern in terms of medicine availability. Notably, half of the HWCs reported not disbursing any medicines for hypertension and diabetes during the month, highlighting issues in providing services for these conditions.

In the HWCs that were part of the study, the primary medicines supplied included Amlodipine, Metformin, and Telmisartan. The extent to which HWCs received their indented medicines varied widely, ranging from 100% fulfilment of their orders to as low as 40%. A particular concern was the availability of Glimepiride, which was lacking in three of the six studied HWCs. For instance, HWC Lalgutwa reported not indenting Amlodipine and Glimepiride in previous months, as they were aware of their unavailability at the Community Health Centre (CHC) itself.

Odisha

All the medicines that were listed under the EDL were available at the UPHC and a three-month buffer stock was maintained as per the guidelines. However, issues emerged related to medicine availability in the District Hospital.

R11 Odisha was taking treatment from district hospital (DH) and shared that most of the time he was unable to get the medication due to unavailability. They mostly don't get all the medications at the same time, for example, they may get two and not get the other two in which case the other two medicines need to be purchased from outside. *"Every time I have gone to the DH, I have ended up fighting with them to get my medication,"* he says. He said he tried buying from Jan Aushadhi Kendra, but many times medication was not available there also so he eventually ends up buying from a local medical shop. Similarly, R10's son in Odisha who was on medication and insulin for diabetes from the district hospital, talked about how in DH, they do not give a full month's medication at a time and he has to go back three times in a month to get his medication.

Suggestions and efforts for better supply of medication and treatment adherence

Even though medicine availability in Chhattisgarh was quite fair, Chhattisgarh state rep 3 pointed out that currently, CHO cannot directly indent drugs from Chhattisgarh Medical Services Corporation (CGMSC) which supplies drug in the state. CHOs have to indent via PHC. PHC on the other hand finds it difficult to understand how the medicine usage has increased so much in recent years (due to the expansion of the programme). He recommended that CHO should be empowered to indent medicines directly (CG state rep 3). He noted that another hurdle could be that the state and districts think that they will have to

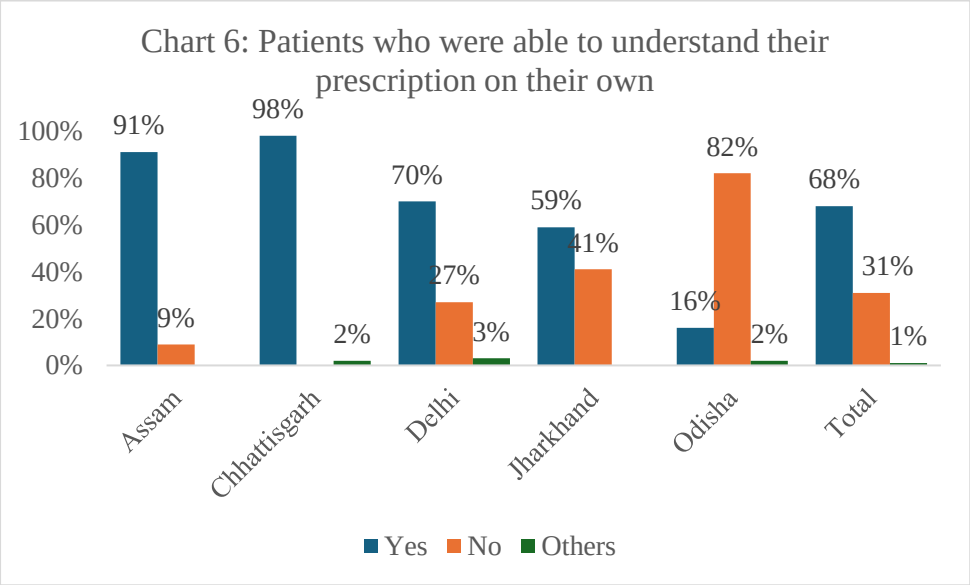
deliver medicines to all the 330 HWCs but he said that is not needed as the medicines can be dropped at PHC and can be picked up by the CHOs (CG state rep).

In the interview with the Jharkhand state rep, there was an awareness and acknowledgment that there has been an irregular supply of medication at the HWCs. He said that based on the experience of trial and error the funds are being directly transferred to the districts to indent their medication as per their requirements.

Quality of medication; health care provider's perception

A healthcare provider in Delhi shared that quality checks are not done for medicines and that many times the pharmacist despite indenting drugs under Essential Drug List (EDL) dispenses less effective generic drugs. He shared an example where in the last 6 months metformin tender was being delayed and the medicine was not in stock. In this case generic and less effective medicine had to be prescribed or doctors had to ask patients to purchase from outside. They gave another example where the medication cover said a different name and the inside capsule of the medication read another name.

3.12 Patients understanding of their prescription.



The data reflects significant variability in patients' ability to understand their treatment plans across different states. According to most patients (68%), they could understand their treatment plan on their own. In Chhattisgarh (98%) and in Assam (91%) patients said they were able to understand the prescription/treatment plan on their own. Whereas in Odisha only 16% patients could understand the prescription/treatment plan on their own.

Those who needed help understanding the treatment plan/ prescription were asked whose help they took. In Odisha, 94% said they took help from another doctor. 85% in Delhi and 66% in Jharkhand took the help of family members. Notably, Jharkhand patients also reported getting help from ASHA (57%) which was much higher compared to other states and 57% in Jharkhand said they also took help from neighbours.

3.13 Patient's preference for certain brand /type of medicines

Related to the issue of patients finding government medicines ineffective, it was observed by the study team in Chhattisgarh that when patients are used to a certain type and brand of medicine, they prefer to take that medicine only. For example, one respondent (male, 60 yrs, hypertension) had a prescription for hypertension that was the same in government and private i.e. Amlo 5mg + atenolol 50 mg. The patient said he preferred to take medicine from the private provider as they give a Fixed-Dose Combination i.e. one tablet. He preferred one tablet over two as according to him more tablets create heat in the body which is not good. The study team had also noticed in general that people considered allopathic medicines not good for health, having side effects (heat in the body) or habit forming. Additionally, the patient spent Rs. 20 to go to HWC to get the medicine (available without cost), while in the village they could buy it for Rs. 50. Therefore by paying Rs 30 extra which is not much of a financial burden they got the medicines they preferred.

Perception of medicines sourced from public health systems being ineffective

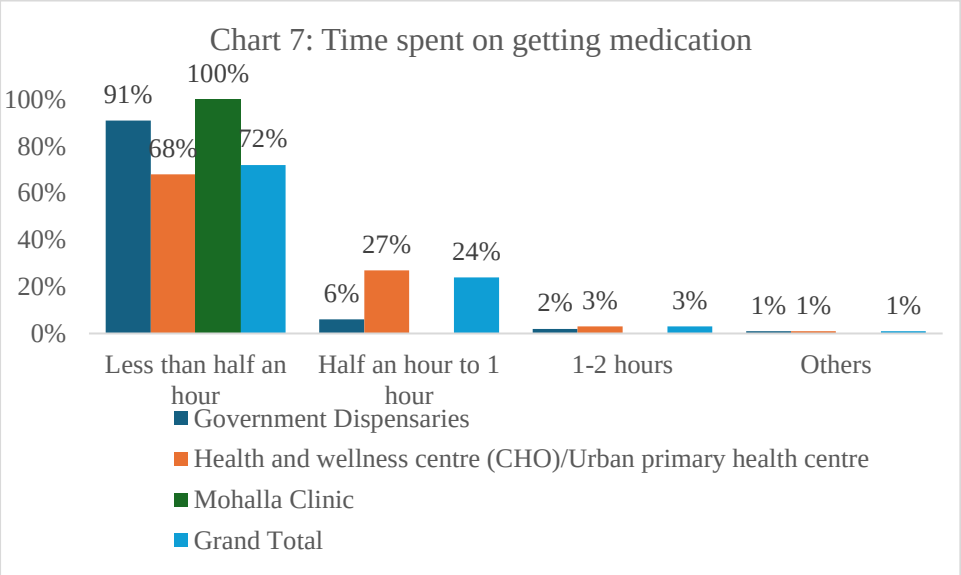
This was commonly observed amongst the patient interviews. For instance, in Chhattisgarh (study team observation and patient responses) where patients had a notion that the government medicines were not effective. *"tablet suit nahi kiya", "Sarkari dawai nahi kaam karti"(medicine from government hospitals are not effective)* was a common worry among people who had tried government medicine. At the same time, many patients in the state were taking medicines from HWC and it was working well for them. One respondent explained that "*even though the medicine does not suit her but it may suit her neighbour. So, it depends on person to person."*

ASHAs in Delhi (Delhi ASHA) shared that *"patients think that medicines in the government supply are not good and they have tried to counsel patients otherwise."*

There was one couple in Chhattisgarh where both wife and husband had hypertension. The husband had found out about his hypertension at a local private doctor but eventually, after being suggested/counseled by the ASHA moved to taking medicines from HWC as it was available for free. Currently, both husband and wife were taking the medicine on alternate days-*"Yaad karke khate hai. Garmi lagte hai .kaam pe jana hota hai (had half medicine, feel very hot due to the medicine and have to go to work)". Because their* BP levels remained normal even when they took on alternate days so they continue taking the medicines that way.

In Delhi, ASHAs also shared that-*"Many times if the packing of the medicine change, then patients start complaining that they want the previous medicines. We try to make them understand that only the pack has changed but the medicine is same"* (Delhi ASHA).

3.14 Time spent on getting medication.



Government dispensaries and Mohalla clinics seemed most accessible from the point of view of time taken to get medicines. State-wise, there was a slight variation observed- in Assam 42% of the patients spend half an hour to one hour in getting their medication as opposed to 24% overall average.

In Jharkhand, no patient spent more than one hour to get their medication for public facilities,. However, after including the private sector, Jharkhand stood out where people spent one to two hours (20% patients) and even two to three hours (9% patients) (n=254) in getting their medicines. This suggests that taking medication from public facilities meant significant time savings for people.

3.15 Transport used to get medication.

While 87-88% in Delhi (govt dispensary/Mohalla clinic) went walking to get their medication, 59% walked to get their medication from HWC/UPHC. Jharkhand shows a high percentage of patients travelling by motorbike (57%) as opposed to 22% overall average when all public and private facilities were taken together. This also corresponds to longer waiting times and greater loss of workdays for Jharkhand described below. In Jharkhand, when taking only public facilities into account, only 5% needed motorbikes as opposed to 11% average for all states. This confirms that in Jharkhand transportation was essentially used to access the private sector. Assam had a high number of boats and e-rickshaws recorded under ‘others.

In the FGDs, ASHAs in Delhi shared that “*the transport barrier is a major reason people do not take medicines (or treatment) from govt dispensaries or mohalla clinic and hence preferred to take medicines from private”* (Delhi FGD).

3.16 Loss of workday in accessing medication

When only public facilities were taken into account, 12 % patient lost a workday in getting their medication. This ranged from 5% in Chhattisgarh to 15% in Odisha. Considering our sample had a larger number of women, this data was disaggregated by sex and revealed that

10% and 17 % of the women and men participants respectively lost a workday in getting their medication.

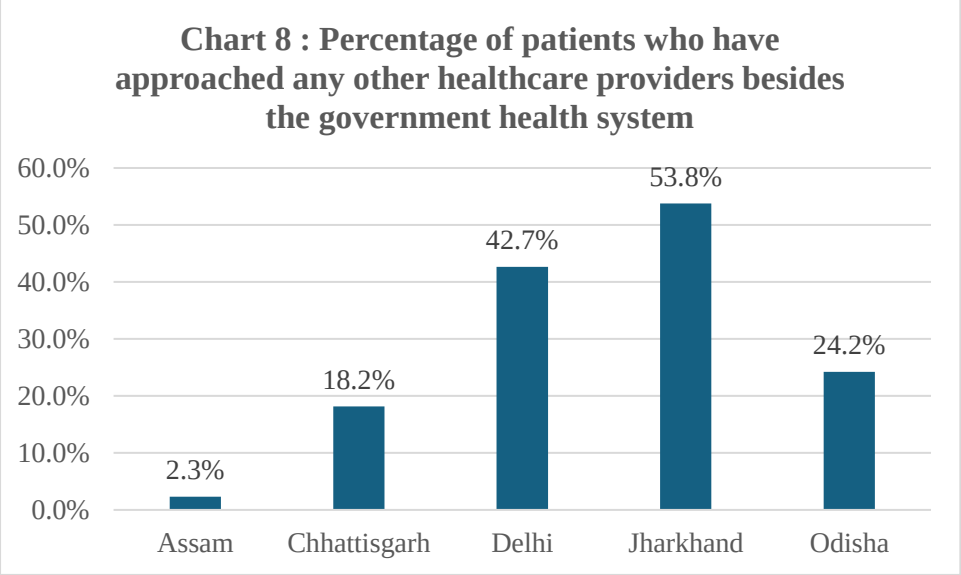
In Jharkhand, it was observed that when solely public healthcare facilities were utilized, specifically HWC, 6% of the patients reported losing a workday to procure their medications. However, this percentage escalates to 23% when patients availed services from public and private healthcare facilities. This rate of workday loss in Jharkhand, necessitated by the acquisition of medication, is the highest compared to all other surveyed states.

> Mohalla clinics proved to be more accessible to people compared to government dispensaries despite their limited use. For the Fifteen Mohalla clinics surveyed, users consistently reported not losing any workdays to obtain medication. They also spent less than half an hour (the minimum time option in the survey) to get their medicines. All fifteen respondents confirmed that medications were either 'always available' or 'available most of the time (75% of the time)'. Additionally, ten out of fifteen respondents stated that they received their medicines every week.

3.17 ID needed for availing medication

In terms of needing any ID to avail medication, only Chhattisgarh stood out in this indicator where 53% (N=276) of people said they needed the NCD card to get their medication. This was also observed qualitatively. Even if the patient could not go themselves, family members took the card. However, it was not very strict and even if the patients did not carry a card, the CHO would enter their register and give medicine considering that they were regular visitors. 8% in Delhi said they needed an Aadhar card to avail of their medication and did not have one. Aadhar was needed to register when the government dispensary was visited for the first time however medication was not withheld in its absence.

3.18 Multiple Treatment Providers and Plans



Highest percentage of patients were in Jharkhand (54%) who had approached a non-government healthcare provider, followed by Delhi (43%), Odisha (24%) and Chhattisgarh (18%) had approached another healthcare provider other than their primary one (See figure above).

Of the people who had approached another healthcare provider besides government healthcare provider, 86% approached a private doctor or an unregistered medical practitioner. In Chhattisgarh, 37% (n=49) had approached unregistered medical practitioners; highest among all states as opposed to 7% average.

Of the people who had approached another healthcare provider, 72% in Jharkhand (n=112) and 66% in Chhattisgarh (n=50), 80% in Delhi (N=51) said that the public and private doctor prescribed different medications. Of all the 1233 people responded, only 4% said they were taking medication from different people at the same time simultaneously.

3.19 Patient's preference for alternative medicine, ayurveda, homeopathy

ASHA's in Odisha shared that "*patients preferred homeopathy for hypertension and diabetes as they feel dizzy after having allopathic medicine."* In another section, issues of patient's aversion to taking allopathic medicines which are life-long, may cause side effects, and are habit-forming according to them, have been discussed.

The pharmacist of an ayurvedic HWC from Chhattisgarh shared that "*people came to HWC Ayurveda as it is in their village, the medicines suit them and there are no side effects in ayurveda*." She added that "*patients make decisions as per their convenience (Suvidha)."*

The following case studies illustrate patients choosing ayurvedic treatment for diabetes (commonly seen in Chhattisgarh) and using different healthcare providers for different ailments.

CASE STUDY R 14 Chhattisgarh: ALTERNATE MEDICINE AND TREATMENT ADHERENCE

Issues:

Dependence on alternate medicine and mixed treatment approach and Treatment adherence

R14, a woman in her 50s from Chhattisgarh with hypertension and diabetes, buys her hypertension medication (Amlodipine 5 mg from the Mankind brand) at a private pharmacy, spending Rs 50 monthly. Diagnosed 5-6 years ago, she began taking these medicines on the advice of a local, unlicensed medical practitioner. For her diabetes, she opts for Ayurvedic treatment, purchasing powdered medicine from an Ayurvedic store in Rajnandgaon district for Rs 30 a month. She consumes a small spoonful of this powder, mixed with *bhuna methi* (as recommended by a neighbour), on an empty stomach. This neighbour introduced her and others in her hamlet to this remedy, which they have been using for many years. The ASHA noted its popularity and perceived effectiveness among many patients in the hamlet. R14 has been consistently using this powder for two years and feels unwell if she misses a day.

CASE STUDY R9 Assam: RELIANCE ON TRADITIONAL MEDICINE FOR DIABETES

Issues:

Belief and reliance on traditional medicine

Influence of family history in use of medication

R9, a 45-year-old diabetic woman from Assam has spent her life in the region. She is a homemaker, living in an earthen house with a pallet roof, and has completed primary education.

While she attends the Piazbari HWC for medication and consults with the CHO, she predominantly trusts and follows the guidance of traditional healers. She frequents a drugstore where a traditional healer practices in her town, placing great faith in his methods. She perceives his treatments as more effective than those provided by the CHO, feeling that her recovery is faster under his care.

Her diabetes was first identified during a community screening. Initially, she disregarded ASHA's recommendation to visit the Piazbari HWC but was later convinced by a health worker. She attributes her condition to genetics, citing her mother's experience with the disease, which was managed without allopathic medicine, only home remedies. She holds the belief that quick recovery eliminates the need for long-term medication.

In her area, many patients prefer traditional treatments for various ailments. Cultural beliefs, easy access to traditional healers, and a deep-rooted cultural reliance on herbal medicine influence this preference. Her description of traditional diabetes treatments includes dietary changes, herbal remedies, and lifestyle adjustments, focusing on plants like bitter gourd, fenugreek, and neem for their supposed blood sugar-regulating properties.

CASE STUDY: COMPLICATION OF PARALYSIS and EVENTUAL NON-TREATMENT ADHERENCE

Issues:

High cost of travel and treatment

Unavailable services at primary level

Multiple health care providers (traditional healer, private doctor)

Accessibility

In Chhattisgarh, it was found that each CHW or ASHA typically had one paralysis case under their care. A case study from the region highlights the significant expenses incurred in treating paralysis. The team encountered a 64-year-old woman with both hypertension and diabetes who had

developed paralysis. She was being treated by a well-known traditional healer from another village, frequented by many from her village, particularly for paralysis cases.

The woman's family spent Rs. 16,000 on treatment and an additional Rs. 2,000 on private transportation every fifteen days, as the healer required her to visit fortnightly. The journey took four hours each way, demanding considerable effort to transport the patient. Despite the financial strain, the family continued this for a year before halting treatment three months ago due to financial and time constraints. Her daughter-in-law reported that, fortunately, the woman's condition has not deteriorated since stopping the treatment.

3.20 Relationship with public healthcare systems and healthcare providers

There was much in the qualitative information regarding the importance, or the skills, attitude and nature of the health care providers concerned to facilitate or inhibit treatment adherence. For instance, R4 Delhi shared about how services have improved after one female doctor joined the DGD. She said that "*this doctor remembers when they do not come to take medicines on time or with a gap which means that our health matters to her*". Similarly, two case studies in Assam showed a lot of trust in one of the CHOs where patients said "*that even when they(patient) go to private, they consult with their CHO first.*" Respondents in a HWC in Chhattisgarh shared that they keep the 'doctor''s phone number and if needed, they called him before going to HWC *"doctor ka number rakhe hai phone karke jate hai (we have doctor's phone number, we call the doctor before visting). ASHA also said "Gaon ke man phone karke jaahee"(villagers call the doctor before visting)*. Most time this would be done through ASHAs. This shows a close interaction between the community, ASHAs and CHO.

Case Study: LACK OF FAITH IN GOVERNMENT FACILITY MEDICATION
ISSUES: **Perceived Ineffectiveness of Government Medicines**: **Combining Private Medication with Government Follow-up**
R12 CG, a 50-year-old woman with hypertension, shared that her blood pressure once reached 160. Initially, she visited a private village doctor who prescribed her hypertension medication. She had tried government facility treatments but found them ineffective, stating, "Sarkari dawai nahi kaam karti" (Government medicines do not work) since she had only followed the government treatment for a week without seeing improvement. Now, she buys her medication, Amodep AT (Amlodipine 5mg and atenolol 50 mg), from a private shop, spending Rs 65 for 30 tablets. She has been on medication for 5-6 years, taking it nightly but alternating days to conserve pills. This self-modified regimen was not doctor-recommended; she even used to take her medicine just once a week at one point. She continues to monitor her blood pressure through home visits by *ASHA* or visits to the HWC. Lifestyle changes, like reducing salt and spicy food, are challenging for her. Her husband, who has diabetes, uses herbal remedies from a popular Ayurvedic shop in Rajnandgaon. A CHO in CG offered an explanation for the perceived ineffectiveness of HWC medications. Private practitioners might prescribe Talmicetrine (Amlo 80), but HWC guidelines start with Amlodipine, and Talmicetrine can only be prescribed by a Medical Officer, not a CHO.

For all the patients who had difficulty accepting the medicines or treatment even in states where it was available, other patients had developed trust in the treatment. In Chhattisgarh in the case of one respondent even if she goes to *Eit Bhatta (brick klin)* for work (5 km away) she makes sure to send somebody with her NCD card to get her medicines from the HWC. One of the respondents said *"Gaon jate hai toh leke chalte hai"(when they go to their villages, they carry with them)."* This was reinforced by another ASHA who said that she tells her patients that they should carry their medicines with them even if they go away from the house and carry them the way they carry money *(paise kee tarah dhar ke jana).*

3.21 Other contributing factors

Majority (88%) of the patients (N=1434) were aware that they should continue taking the medication to control the disease, and 92.3% of patients were satisfied with their healthcare provider (N=1429).

Seven patients said they were dissatisfied or extremely dissatisfied of which five were from Delhi and one each from Chhattisgarh and Odisha. One was not taking any treatment, three were taking treatment from government facilities, and three were taking treatment from a private medical shop or RMP.

Even though the majority of patients felt that the disease could be controlled by having medication it was not a smooth transition for them. Initially patients appeared hesitant to accept the diagnosis and the medications as mentioned in previous sections. One of the reasons; apart from having to accept a lifelong condition, was also related to fears of 'addiction' to medication that was shared in several conversations.

"*With chronic diseases like hypertension and diabetes, many patients fear that if they start having medicines once, then they have to keep having them forever*" (CHO CG 2, Ambari FGD, Assam state rep 1).

It was found in some cases in Chhattisgarh that people had stopped taking medicines, got worse, and then started taking them again regularly and this was echoed by an Assam state official also (Assam state rep 1). For ex- Budhavarin in Chhattisgarh a patient shared that she stopped medicines in between because she was feeling well. Then one day she got very sick and fainted and since then she has been taking her medication regularly.

In Chhattisgarh, the study team came across a few patients who were taking medicine fearing they might get *lakwa*/paralysis. A 35-year-old girl cried a lot during conversation because she had hypertension and was scared that she might get *lakwa/* paralysis.

ASHAs were aware of the fear of complications of the disease among the patients. The fear of complications was used as a way of ensuring treatment adherence mainly by ASHAs to ensure that patients take medicines, and their conditions does not get worse. In Jharkhand for example ASHAs responded that they inform patients that "*if they do not do regular check-ups, hypertension may lead to brain haemorrhage and paralysis, or said that it is a disease that needs to be controlled from the start"* (JH ASHA). Similarly in Delhi, the ASHA informed the patients that "*that if your sugar level goes too up, it will affect your kidney."* The same was observed in Chhattisgarh too.

ASHAs in Delhi shared that older people want to take medicines but the younger people just above 30 years do not want to. They added that patients "*have a fear that if they find out about some disease, they would get stressed and would have to take medicine.*"(Delhi ASHA)

3.22 Treatment adherence in terms of modifications of living conditions

Table 22: Adherence to lifestyle modifications

Adherence to life style modifications (N=1280)	**%**
Food related advice	
Avoid eating food high sugar, salt and fat foods like packaged food	73
Avoid salt rich foods(pickles, namkeens etc)	61
Drink plenty of water	59
Consume a variety of fresh, seasonal and locally available fruits and vegetables	56
Decrease excess amount of tea, coffee and cold drinks	44
Reduce consumption of deep fried foods	35
Restrict intake of red meat(like mutton, liver etc)	31
Eat whole cereals and pulses(with peel)	16
Consume lean meat (chicken, fish)	15
Exercise Related	
Do moderate exercise for at least 150 minutes per week	12
Choose activity that fits into your routine	11
Do regular exercise	19
Do brisk walking, jogging, cycling, dancing, playing sports, yoga	7
Carrying/moving moderate loads(less than 20 kg)	6
Do activities that increase the heart rate	2
Do yoga	10
Exercise in groups	0
Substance abuse related	
Avoid the use of tobacco in any form	20
Avoid the use of alcohol	11
Nothing mentioned	1

The data shows that patients were able to make certain changes in their lifestyle, that is in their diet, exercise habits and dependence on substances to some extent. When asked if they could follow any of the changes they were suggested by their healthcare providers, a majority of the participants (73%) said that they were able to make dietary changes and that they avoided eating food with high sugar, salt and fat, followed by 61% patients saying that they are able to avoid salt rich foods like pickles etc., 59% patients said that have been able to increase the intake of water and 56% patients said that they have started consuming more fresh fruits and vegetables that are locally available.

The study also found that patients had an understanding of how their conditions of both hypertension and diabetes were related to stress or tension.

For instance, R 4 Delhi said her sugar & blood pressure levels tended to increase when there was stress in the house and also saw it as a cause for the disease. A respondent from Chhattisgarh said- *"Agar ghar mei shanti rehte hai toh goli nahi khana padhta hai (if there is peace at home, then I don't need to eat medicine). Zyada ladai hote hai toh mai behosh ho jati hoon"(I faint, if argument/fight happens at home).* Another interview respondent in Chhattisgarh when asked when her hypertension was diagnosed, responded *–"jis din bahu ke accident hue us din se BP badhe hai (10-12 saal pehle)"(the day my daughter in law met an accident, my BP has been increasing, its been 10-12 years now).* R10 Odisha's son shared

that there are times when he is unable to take his insulin and it happens when he is facing stress or issues in his business as the survival of the family depends on his income. He feels weak when he stops taking insulin, but feels fine after taking it. R11 Odisha felt that the stress of surviving and feeding a family and solely dependent on his street-food business was the cause of his diabetes.

3.23 Access issues among patients with specific vulnerabilities

It was clear from the survey that the elderly have a specific challenge with respect to accessing treatment and adhering to it. Most of this relates to relatively lower mobility and lack of support systems such as wheelchairs or proper roads as well as a greater dependence upon family members for many aspects of their care including sourcing medicine, being accompanied to the health care centre, purchase of medicines and needing reminders to take medicines on time.

One ASHA in Chhattisgarh shared that one case under her (female, 62 yrs) has 165 BP but has not started any treatment- "*kehte hai legaiya nahi hai"* (nobody to take to the hospital). ASHA added that the patient insists that they make an SHC in the village after which she will take treatment as she won't go to another village. ASHA shared that even though the woman has 3 sons, only one is 'good' but he also does not get time. This mobility issue for old patients was reiterated by other ASHAs also in Chhattisgarh.

CASE STUDY: Discontinuation with medication due to access issues
The patient lives with her young nephew who she says does not live with his family as he has mental health issues. The patients says that she works as a farm labour and earns daily wages which helps in feeding herself and her nephew in addition to an old age pension of 1000/- per month. Even though her brother's family lives nearby they do not assist her in anyway. The patient got to know about her disease through the NCD camp that is regularly held at the Anganwadi centre in the village. The NCD camp in the Anganwadi centre is done by the CHO, ANM and ASHA. It was during this NCD camp 4 to 5 months ago that she was diagnosed with diabetes. It was during the same visit that she was given the medication for diabetes. When she was diagnosed she was also given some advise on the kind of food she should not be eating. She was told not to eat potato, decrease rice intake and not eat vegetables that grow underground. She was also told to eat more vegetables. She started taking the medication which she had for a month or two but left it when she got a fever. Once she was better she tried to visit the HWC at least three time to consult with CHO but was unable to find the CHO at the centre and the centre was closed. Twice she went alone and once with the ASHA; even though the ASHA had called ahead, they were still unable to meet the CHO as the CHO had to go for a training session. She walked to the HWC but as she is old and has pain in her legs, even walking is a difficult task for her. Reaching the HWC takes more than an hour and to reach the HWC with so much effort, time and pain, and not find the CHO becomes very demotivating. The patient pointed out that reaching the HWC on foot is even more difficult due to weather conditions whether it is extreme heat that they had been facing or the torrential rain that they are currently facing. The patient has been suffering from shivering, weakness, joint pains for the past few years. The patient said that she wants to continue the medication and wants to get better. She also says that she reflects to herself that how long would this disease last, and if she would ever feel better. Upon asking if she was ever really informed that for how long would she have to suffer from the disease, no one really told her about it (not CHO, not ASHA). The only thing that she was told by the CHO was that she must regularly take her medication. Hence, she wants to start taking the medication again only once she has consulted with the CHO.

One of the major life change that she has had to do was to reduce the intake of potato though it was a major part of her diet earlier. Even though she was informed that she was not suppose to eat sweet things, she said she was not eating sweets anyway.
At the end of the interview the patient suggested that the ASHA should be allowed to give the medication at her home instead of going to the HWC centre.

CASE STUDY:

Key findings: informal support group among old women going to HWC, sharing experiences, Support of ASHA

The patient has two sons; her daughter passed away, and her teenage granddaughter and her bedridden husband live with her. Despite sharing the house with her children, they use a separate cooking stove for their food. She cultivates her small land and sells crops from that in the local market. Her primary income is from her old age pension from the government. She learned about her diabetes and hypertension at Katarpa HWC. Initially, she received medication from the HWC but stopped due to a lack of improvement. She then sought help from an unregistered local practitioner in the village, which helped temporarily but became unaffordable. She resumed getting free medication from the HWC and was advised to eat healthier without receiving a written prescription. But she was informed that her health was okay upon checking her vitals. She thought that meant that the disease had gone away, even though she had to continue taking the medication. The CHO verbally guided her on medication usage. ASHA is helpful and helps coordinate group visits to the HWC. She wishes for home delivery of medication due to difficulty in traveling to HWC and walking those few kilometers, which become more difficult in rain. Her granddaughter assists in daily tasks and reminds her of medication. She is concerned about her health but cannot afford private treatment and has to make do with the treatment at HWC.

Accessing medical care from the HWC is challenging due to its considerable distance. The difficulty is exacerbated by the HWC frequently being closed, which hampers consistent access to necessary medication and health services. This situation is particularly burdensome for elderly individuals who find it arduous to reach the center due to their age-related limitations. Compounding the problem is the need for clearer communication from the center regarding improvements in their health conditions after receiving treatment. Despite these hurdles, a silver lining emerges in the form of an informal support group among older women who share their experiences while journeying to the HWC. This camaraderie helps them navigate the challenges together. Additionally, the presence of ASHA, or Accredited Social Health Activist, plays a vital role in bridging the gap by providing support, coordinating group visits, and reminding patients of their medication.

GD, Jharkhand

The wounds on the leg do not heal. Even though I have glasses I am not able to see clearly. I am putting eye drops. I am not able to put it myself, but have to ask them children living around to come and put it for me in the eyes. ASHA had taken me to the Sadar Hospital, Ranchi, where the doctor gave me the prescription. First we had to walk 2km or so, to get to the main road to get a shared auto. We had to change the shared auto more than 3-4 times to reach the hospital

They gave me only one drop…rest have to be purchased from outside. They did not explain as to for how many days it has to be taken, but only said that it has to be taken 5 times. They said that I should purchase from outside. The doctor had prescribed me three medicines, but I could not buy the two because I did not have money.

The other thing is that there is nobody to take care of me, then what can I do. I have sons and grandsons. But they don't even come to ask about my health. They live nearby only. I live alone in the

house. Son and all, nobody is here. No one even comes to see me. No even comes to check if I have eaten or not. No one is there only, what can I do now. The son is not concerned at all if I not well or if I am in pain.

I am not able to wash the utensils also. I am not able to make chapatis, I am unable to put utensils on the gas. I am only eating rice. What can I do, I cant cook only. I am not even able to start the gas…The neighbor's children do it for me sometimes. I just call out to them.Earlier I used to eat a lot of potato but because of sugar that also has reduced. Some times relatives and neighbors cook and give to me.

I cant walk at all..full body shakes when I walk. Even my sister in law suffers from this health issue. We both are unable to walk. Only us two have this for more than 4/5 years. When I was unable to walk, I had gone to the doctor and then I was told that I have this disease. I did not have any fever or anything. It was only when I was having issue in walking or getting up.. that I was not feeling well..nobody was even there to take me to the hospital. Before that I did not know that I have this disease.

Where can I go, my body is not moving only, what can I do it has been 5 years..

The first time I had gone to HWC doctor, where my husband earlier used to work. We all had medical card etc. There only I got to know that there is diabetes. I have been eating so much medication but nothing has changed..is it a small thing, 4/5 years? For two years I had from HSC, then I showed to a private doctor also.. I tried medication, used oils and all for pain in the feet, but after so much medication it has not been effective. I still continue to take the medication. I have eaten a lot. I also tried to eat the jadi buti medication. I did feel a little better after having it.

I am old, I can't work also. I have no income and have to go to the government centre to get medicine. The centre is not very far, it is less than 10 minutes from here for a normal person but it takes much longer for me. I walk very slowly and take support of stick to go to the HWC. Without the stick I am not able to walk. Sometimes the ASHA gets it.

I have to depend on others and whatever they give and whatever god sends my way. He is the almighty - happiness, sadness, health all he sees.

3.24 Treatment adherence among insulin users

Out of total patients interviewed nineteen patients had taken insulin injections at any point of time across study sites of which twelve were from Delhi. For thirteen patients, the study team was able to do more in-depth interviews after obtaining the patients' consent and was able to get further information. As is evident from the site description, four interviews were available for patients belonging to a rural area and this itself may be reflective of a challenge in identifying insulin requirement. Of these, nine said they started insulin more than a year ago, two patients said it had been started between six months to a year ago with the remaining two having been advised insulin very recently. A thematic analysis was done of these interviews and the findings related to TA are presented below.

Additionally, case studies were conducted with 5 insulin users for greater detail.

Table 23: Insulin users across states

State	Insulin users (Interviewed)
Assam	1 (1)
Chhattisgarh	1 (1)
Delhi	12 (9)
Jharkhand	2 (2)
Odisha	3
Total	**19**

3.24.1 Sources of Medical Advice for Initiating Insulin Therapy

The data suggests a diversity in medical advice concerning the initiation of insulin therapy, highlighting the role of both private and public sectors in patient care. The data also indicates that patient decisions on starting insulin were influenced by various factors, including the credibility of the healthcare provider, personal experiences, and possibly the perceived quality of care.

There was a recurring mention of private MBBS doctors across the responses. This suggests that many patients received their initial advice regarding insulin from private healthcare practitioners. However, medical officers at government dispensaries and doctors at urban hospitals had advised some patients to start taking insulin.

One patient initially refused to start insulin when advised by a doctor at Kasturba Hospital (a government medical college in Delhi) but decided to follow a private doctor's recommendation a year later. This change over time reflected various factors, such as the progression of disease, change in personal health perception, or increased trust in a different healthcare provider.

Several patients had been advised by multiple medical authorities, including private and government-affiliated practitioners indicating a search for second opinions, confirmation of diagnosis, or a need for more clarity in the initial advice received.

3.24.2 Information given to patients for insulin

Twelve out of thirteen patients were given information on why insulin was being started for them. Only one said he/she did not remember. All 13 were explained how to take insulin injections.

Of the thirteen patients, six were told about side effects, the other six were not, and one patient was not sure if she was told about the side effects. Of the six patients who said they were informed about the side effects, five were told to “take some sugar/glucose immediately”, while one was told to go to government dispensary by the healthcare provider.

The data consistently indicates that patients were informed about the reason for starting insulin was which is critical for patient understanding and compliance.

All patients, except one who did not remember, confirmed receiving explanations on administering insulin or injections. Private MBBS doctors were frequently mentioned as the initial source of instruction for taking insulin. However, there were notable mentions of other sources, such as government medical officers and doctors from public hospitals or a medical college.

There is a correlation in most cases between the practitioners who advised starting insulin and the one who instructed on its administration, with private MBBS doctors being a common

factor in both. However, there are instances where the diagnosing and instructing practitioners differed, indicating that patients may receive care from multiple sources.

Advice to "take some sugar/glucose immediately" in response to side effects was a common finding, demonstrating a universal first-aid response for hypoglycaemia, a common side effect of insulin therapy. The single instruction to "go to government dispensary" (government dispensary) in case of side-effects suggests that in some cases, patients were also advised to seek professional medical help if they experience side effects. This implies a dual-layered approach to managing side effects: immediate self-treatment followed by professional medical assistance.

3.24.3 Storage related information

The uniform response of "Yes" in terms of how to store the insulin across the board showed a consistent effort to educate patients about the proper storage of insulin, which is crucial for maintaining its efficacy. Insulin is sensitive to temperature and handling. The fact that instructions had been provided suggests that healthcare providers are ensuring that patients are aware of the importance of proper storage conditions to prevent degradation of the medication.

However, field observation suggested that refrigeration was not always being followed for the open vials in current use as the fridge might belong to neighbours.

R11 Odisha mentioned that when he first learned he had to take insulin, he had to borrow money and buy a second-hand fridge first to keep the insulin.

3.24.4 Insulin availability across states

Interestingly, conversations with CHOs revealed that they were either ignorant about being able to requisition insulin for users in their area or were not utilising the facility claiming that patients preferred to buy it from private sources. However, conversations with insulin users in the community suggested that they would welcome the savings if they could get insulin free from the public health facilities.

Across states, it was found that insulin was not available at primary-level facilities. In Assam, it was shared that as per guidelines, there is no provision of insulin at the primary or secondary level. It can only be started at the tertiary level as specialist knowledge is needed for it (Assam state rep 1 and 2). Similarly in Delhi, it was shared that insulin is not available at the dispensary level as that is not the mandate according to the MO. It is available at the polyclinic dispensaries where an NCD specialist visits and prescribes insulin (Delhi state rep).

The findings were reinforced in the data and case studies conducted with insulin users as discussed below.

3.24.5 Source of obtaining/purchasing Insulin

The data indicates various initial sources from which patients received insulin. Private hospitals were the most frequently mentioned source for obtaining insulin for the first time. Few patients also received their insulin from government dispensaries. Institutions like Arvind Hospital, Lady Hardinge Medical College, and LNJP Hospital were specified as sources of insulin in Delhi. While private healthcare facilities were a primary source for patients beginning insulin therapy, there is evidently a diverse ecosystem of care providers, including government facilities, specific hospitals, and retail pharmacies.

The data outlines various current sources from which patients obtain insulin. Many patients continue to get their insulin from private pharmacies and medical shops, suggesting easy access, convenience, or preference for private retail as a source for their medication. There is a consistent reliance on private hospitals for insulin; this reflects the previous pattern where private hospitals were also a common source for the first insulin acquisition.

When comparing the sources for the initial acquisition of insulin to the current sources, it is evident that patients continue to utilize a mix of private and public healthcare services. While private pharmacies and hospitals are frequently cited in both datasets, there seems to be an ongoing, albeit less prominent, role for government dispensaries in current usage.

HWCs did not find mention in the analysis of information from insulin users and obviously the primary facilities were not catering to the patients needing insulin. However, in Delhi, from the case studies documented, the availability of insulin seemed to depend on the type of dispensary. For example, one patient shared that insulin availability was good at Ballimaran DGD which is a polyclinic, while another patient shared that insulin is not available in Sitara Gali Dispensary (DGD Ajmeri Gate). In Chhattisgarh too, insulin was not given in any of the HWCs. In Odisha, the two insulin case study patients were taking it from District Hospitals and struggled with the time consumed in accessing it. Similarly others in Delhi and Odisha confirmed that they would take oral medications for hypertension and diabetes from the dispensary/ UPHC but insulin from private sources as going to the government hospital for insulin was time-consuming. The issue of waiting times and distances came up in several case studies as a reason for accessing insulin from private sources, albeit with OOPE.

R5 Assam reported how he travels about 25 to 27 kilometres to acquire his monthly insulin from a private doctor.

3.24.6 Expenditure on Insulin

Ten out of thirteen patients were getting their insulin from private sources and incurred out of pocket expenditures. The other three were taking insulin from government dispensaries and tertiary-level hospitals in Delhi and therefore did not have to pay for their insulin which might suggest better availability of subsidized (in case of Jan Aushadhi Kendra) or free healthcare services in the capital city. Of the ten patients who were paying for insulin, five patients were paying under Rs. 1000 per month, four patients were paying Rs. 1000-3000/month and one patient was paying above Rs. 5000/month. Additionally, seven of these ten patients also mentioned spending under Rs. 1000 on pen/injector/injection in a month. Eight of these ten patients also said they were spending different amounts (from Rs. 0-Rs. 300 and above) on injections. Thus, while some diabetic patients were able to obtain insulin at no cost, particularly those utilizing government facilities in Delhi, there is an additional layer to consider—the availability of insulin syringes or pens, which are essential for insulin administration

There was only one patient out of twelve who said she/he had taken insulin only half of the days in the last one week. This patient was not using insulin as per prescription as they did not have money to buy it; it seemed the patient was rationing their insulin.

For a patient in Assam “his monthly insulin and travel expenses come to Rs 5000.”

In the case of R10 from Odisha, a 75-year-old diabetic woman with kidney problems was “receiving insulin treatment from a private hospital, incurring a monthly expense of Rs 6000.” Her care was shared between her sons. Previously, she had sought treatment at the district hospital (DH) but found it inadequate. Her son, also diabetic and on insulin, was getting his treatment from DH, where treatment, medication, and insulin were free. However,

he was dissatisfied with the treatment's effectiveness. Despite this, “he still spent Rs 3000 on his treatment.”

Considering the fact that OOPEs may significantly lower TA to insulin, it is important to take these facts into consideration in the planning and implementation of any NCD programme for better treatment adherence.

In a case study in Odisha a patient faced challenges in accessing treatment at DH, including the need to rent a vehicle for the hour-long travel, long queues at the hospital, and the requirement to see a specialist for medication. Visiting DH often resulted in a day's wage loss. Sometimes, he resorted to buying medicine from the private sector. The patient also mentioned that “he could not get a month's medicine supply in one visit and had to visit DH thrice monthly.

The researcher noted that these challenges could be mitigated if insulin were available at the Urban Primary Health Centre (UPHC).

3.24.7 Attitudes to Insulin treatment

At present, all patients felt comfortable with the self-administration of insulin. Starting insulin therapy often involved a learning curve. It was not uncommon for patients to experience apprehension, particularly related to the use of needles. This initial fear sometimes necessitated the support of family members or local healthcare providers to administer injections. Some patients still required help at times, which was due to various factors such as physical limitations as with elderly patients or a resurgence of needle anxiety. The role of family and local healthcare providers as part of the support network was crucial, especially during the initial phase of therapy.

3.24.8 Preference to alternative medicine

One woman patient who was on insulin said “it affects her financially but also emotionally as it is something she has to her entire life and it is painful.” She reflected that she is thinking of taking homeopathy as the disease is for a lifetime and for how long can she take such medication and keep purchasing also.

3.25 Out of Pocket Expenditure (OOPE)

3.25.1 Expenditure on medication

Most patients; 68% indicated they 'never' pay for their medication. However, a substantial number, 24% stated they 'always' pay for their medication.

Table 24: Patients currently paying for medication

Patient Response	**Number of patients(N=1410)**
Never	68% (964)
Rarely	1% (20)
Sometimes	4% (57)
Most of the time	2% (24)
All the time	24% (339)
NA	0.4% (6)
Total	1410

Table 25: State-wise patients paying for medication

Currently have to pay for medication(N=1410)	Assam	Chhattisgarh	Jharkhand	Delhi	Odisha
Never	98.4% (302)	85.9% (237)	29.2% (76)	62.6% (186)	60.4% (163)
Rarely	1.3% (4)	1.1% (3)	1.5% (4)	1% (3)	2.2% (6)
Sometimes	-	2.5% (7)	4.2% (11)	3.7% (11)	10.40% (28)
Most of the time	-	-	1.2% (3)	-	7.8% (21)
All the time	0.3% (1)	10.5% (29)	61.5% (160)	32.7% (97)	19.3% (52)
NA	-	-	2% (6)	-	-
Total	**307**	**276**	**260**	**297**	**270**

The data from Assam shows that most patients (98.4%) do not have to pay for medication. In **Chhattisgarh**, a significant majority (85.9%) do not pay for medication. Jharkhand stands out with the highest percentage of patients (61.5%) who always have to pay, and Delhi and Odisha present a mixed scenario with a divide between those who do not pay and those who consistently bear medication costs. In **Delhi, o**ver half of the patients (62.6%) do not pay for medication, but a sizeable portion (32.7%) always pay, and 1% rarely pay. I**n Odisha, a majority** (60.4%) do not pay for medication, but nearly a fifth (19.3%) always pay, and some patients pay sometimes (10.4%) or most of the time (7.8%).

These findings are entirely consistent with the emerging picture of relatively well functioning public health systems in Assam and Chhattisgarh and high prevalence of privately accessed care in Jharkhand with mixed pictures in the two urban locations.

3.25.2 Detailed description of Out-of-Pocket Expenditure

Table 26: Detailed Out of pocket expenditure

On what all did patient have to spend money on	No of patients(N=1364)
Nothing	61%
Travel	20%
Lab testing	6%
Medication	32%
Consultation	4%
Insulin/injection	1%
Hospitalisation	0.1%
Supplements	1%

A significant number of patients incurred expenditures related to travel with 20% of patients having to spend money on travel for medical services. This expenditure highlights the additional indirect costs associated with accessing healthcare. Lab testing accounted for expenses in 6% of patients. A smaller percentage of patients, 4%, had to pay for medical consultations, 1%, had to pay for insulin or injections and a minimal number of patients, 0.1%, reported expenses related to hospitalisation.

Table 27: State wise detailed out of pocket expenditure (%)

Items where money was spent	Nothing	Medication	Travel	Lab Testing	Consultation	Injection/ Insulin/supplements/others/hospitalisation	N
Assam	99	1	0	0	0	0	**307**
Chhattisgarh	69	13	20	0	1	1	**271**
Delhi	49	36	20	12	0	5	**301**
Jharkhand	28	70	38	1	3	0	**253**
Odisha	49	46	27	17	20	3	**232**
Grand Total	**61**	**32**	**20**	**6**	**4**	**2**	**1364**

The data shows considerable variability in healthcare expenses across states. Assam stands out with the least out-of-pocket expenditure, while Jharkhand shows the highest percentage of patients paying for medication and travel. Travel and medication expenses are significant in Chhattisgarh, Delhi, Jharkhand, and Odisha.

3.25.3 Range of Out-of-Pocket Expenditure

A gradient of expenditure illustrates varied levels of financial burden among the patients.

A large majority, 77% of patients, fall into the out-of-pocket expenditure range between Rs.1 and Rs.1000 monthly. A significant minority, 21% of patients, incur moderate OOP expenses, more than Rs.1000 but less than Rs.4000 monthly. A very small proportion, 0.2% or three individuals, reported extremely high monthly expenses, with one patient spending Rs. 9000(Jharkhand) and two individuals spending Rs.20,000(both in Delhi).

Table 28: Out of pocket monthly expenditure for patients

Out of Pocket monthly expenditure (in rupees)	%	Number of Patients (N=1344)
Nothing was spent	61.6%	828
1-100	9.5%	128
101-200	4.7%	63
201-400	6.5%	87
401-600	4.9%	66
601-800	1.8%	24
801-1000	2.1%	28
1001-1200	0.5%	7
1201-1500	1.4%	19
1501-2000	2.7%	36
2001-3000	2.5%	33
3001-4000	1.0%	13
4001-5000	0.7%	9
5001-10,000	0.1%	1
20,000 and above	0.1%	2

Table 29: State wise Average OOPE in a month

Row Labels	Average monthly OOP (for those who spent any money)	N (number of people who spent any money)
Assam	2675	2
Chhattisgarh	104	83
Delhi	763	132*
Jharkhand	535	179
Odisha	2075	114
Grand Total	**877**	**510**
**This includes two cases in Delhi where out of pocket expenditure was Rs 20,000 in a month.*		

With an average OOP of Rs.104 across 83 patients, Chhattisgarh presents the lowest average OOP expenses; with an average OOP of Rs. 2075 from 114 patients, Odisha's average is on the higher end.

The out-of-pocket expenditure in Odisha is almost equally incurred across public and private healthcare services. Urban Primary Health Centre reported 50% of OOP expenses by patients. **Private MBBS Doctors and Private Unregistered Clinics** constituted 46% of the OOP expenditures by patients. Relatively more patients incurred OOPE on medication when they were getting their current treatment from UPHC.

Assam had two outlier cases where average expenditure was Rs 2675 out of which one of the patients was going to the HWC for treatment. This patient who was getting treatment at the Piazbari HWC was coming from a village(Sadhubasa) that was far from the HWC and he had to travel by boat to reach the HWC and spend somewhere between Rs.300-400 rupees a month for travel to reach the HWC. One patient was taking insulin and consulting a private doctor in Kolkata and had to spend around Rs.5000 for the treatment and travel.

3.26 Prescription analysis

3.26.1 Prescription vs medicines being taken.

During the patient interviews, patients were requested to present their medications and accompanying prescriptions for review. The data thus obtained from these two parameters—medications in possession of the patient and prescription details—were documented and later analysed. This comparison aimed to ascertain the degree of similarity between the prescribed medication regimen and the patient's actual medication intake.

For Assam and Chhattisgarh, a random check was done of ten patients considering prescription and medicine information were clear from the survey. An online random number generator was used for this. For Odisha, Delhi and Jharkhand, since there were a smaller number of fields which were filled/ available, the team checked all that were available. The findings from it are below-

Assam

Very clear and complete information was filled for Assam for all the 309 patients. Amlodipine 5 mg was mainly prescribed for hypertension, with a few patients receiving 2.5

mg, and metformin 500 mg for diabetes. It can be seen that most patients were going to HWC in Assam and these are also the medicines for hypertension and diabetes as per HWC protocols. In very few responses losartan, glimezide, glimestar, telmisartan were prescribed and they were being taken as per prescription.

All the random ten checks had impressively consistent information where prescriptions and medication matched in terms of name, dosage and frequency.

Chhattisgarh

In Chhattisgarh, some of the prescriptions were clear and filled. Others said that their prescription was not made, they did not have it, or it was old or not updated. Observations also showed that a significant number of HWC NCD cards were not updated.

Of the ten cases for which a random check was done, four patients (taking medicine from HWC) were taking Amlodipine 5 mg or Enalapril 5 mg or combination of both for hypertension as per their prescription. Two patients, both having both hypertension and diabetes were taking medicines from HWC according to their prescriptions. It was observed by the research team that two patients on medication from HWC for hypertension were taking Amlodipine 5 mg but the prescription was old and illegible so a comparison was not possible.

In Chhattisgarh, a diabetes patient in his late 30s was mistakenly taking Glimepiride and metronidazole instead of metformin and Glimepiride, as noted in his NCD card. This mix-up likely occurred because the prescription was abbreviated to "met," leading to the dispensing of metronidazole instead of metformin by the CHO.

The study team informed this to CHO and called the patient to the HWC to correct his medicine.

Another household in Chhattisgarh was found where an old patient was giving a different medicine to his wife than the one prescribed and the confusion seems to have happened as both the medicines looked alike. This was reported to ASHA and the patient by the team.

One woman taking medication from DH was taking gumstar- M1 tablet for diabetes. She did not have the prescription. Another patient taking medicine from HWC was taking metformin for her diabetes. The prescription provided to the patient specified metformin; however, it lacked details regarding the dosage and frequency of administration.

Delhi

For Delhi, many responses indicated that prescriptions were either missing or unavailable. Approximately ten out of 115 patients reported that their prescriptions were digitized, implying that while the healthcare facility retained a digital record, the patients themselves did not possess a physical or digital copy of their prescriptions.

Random check- For Delhi out of 303 patients, the team selectively checked all the fields where medicine information and prescription information were available. Five cases were found in total with differences in medicine and prescription information. In one case, being treated at the government dispensary, metformin was prescribed for diabetes but vildagliptin, and glibenclamide were being taken. For another patient with both hypertension and diabetes, also being treated at the government dispensary, Amlodipine was written in the prescription while vidylimptin and metformin were being taken. For another patient with both hypertension and diabetes who was also being treated at the government dispensary, only Amlodipine was written in the prescription, while metformin was being taken. In another case, for a patient with both hypertension and diabetes, glimepiride, and metformin were prescribed but envas was being taken.

In the Shahganj area, most patients received treatment from government dispensaries or health facilities. However, in the Farash Khana area, it was observed that the majority were seeking treatment from private sectors or buying medicines from unauthorized pharmacies without prescriptions. Some had prescriptions but had either discarded or misplaced them. Additionally, there were cases where patients treated at government facilities had prescriptions but were reluctant to show them. There were also instances of patients without physical prescriptions but with digital health records at the facility. This was noted by the state team in Delhi through observation and informal interactions.

Jharkhand

Only five out of 253 responses provided, information on prescriptions even though at least 22% of the respondents were going to HWC for medicines. The study team learnt that in HWCs in Jharkhand, no NCD/prescription cards are being given. HWC maintains a register and gives medicines as per that. The state study team shared that during the research study when people were asked for a prescription, they would show medicines instead. However, more recently (after our study), NCD cards have started being given. Evidently, though a large proportion of surveyed patients were accessing the private sector, there too, documents were ostensibly not being provided.

Regarding the variety of medicines being consumed, it was observed that in Jharkhand, where there is a notable reliance on the private healthcare sector patients were prescribed a diverse range of pharmaceutical brands. This is in contrast to the limited brand variety, typically Amlodipine and metformin, commonly dispensed in the government health facilities at the primary level.

Odisha

In Odisha, prescription booklets were given by UPHC but not all patients had it or kept it safely. Patients showed old medicines in the UPHC to receive more medicines.

A check of all available prescriptions (43) revealed that all cases had the same information on medicines being taken and the prescription. Apart from this, in one case (UPHC) metbetic was being taken instead of metformin prescribed. In two cases being treated at the UPHC, Glimepiride and metformin were prescribed but only metformin was being taken. In another

case, Glimepiride was prescribed but Glimepiride and metformin were being taken. Aside from these instances, the remaining patients adhered to their prescribed medication regimens per the provided prescriptions.

3.26.2 Observations from prescription photos

A total of 102 prescriptions were examined by a medical practitioner for legibility; considering the fact that patients used multiple sites to access their medicines. These were selected randomly from all states except Jharkhand where only six prescriptions were available and all were examined.

Overall, 80% of the prescriptions were considered legible. Assam fared excellently with 100% legibility followed by Delhi and Odisha. Jharkhand fared poorly with four of six prescriptions being illegible. The entire set of prescriptions from Assam were from the public sector. Notably, only 10% of the prescriptions were written in capital letters, most of which were from Assam. Upon examination of the prescriptions and booklets in the possession of the patients, it was observed that a relatively small proportion of individuals (8-14%) had prescriptions from private practitioners. In contrast, public healthcare institutions are fulfilling their documentation responsibilities, with most patients (86-92%) possessing prescriptions issued by government facilities. The overall impression of the reviewer was that the documents were sufficiently legible not to be a constraint for treatment adherence by way of causing confusions amongst dispensers in various facilities being used by the patient.

3.27 Examining the interventions planned for treatment adherence under universal screening of NCDs in different settings.

3.27.1 Screening of hypertension and diabetes at health facilities

In terms of screening for hypertension and Diabetes, in Assam, two HWCs (Piazbari and Ambari) had the best population-to-screening ratio with one third to almost two third of the population screened; given that about 50% of the total population would be over the age of 30 years . The other two HWCs (Gobardhanpara and Khankhowa) had only 5and 13% of the total population screened respectively. In Chhattisgarh, it was difficult to get the numbers for the screened or diagnosed patients in the HWCs. The data with the CHOs (if they had complete information) was different from that entered in the NCD portal. The district-level staff and CHOs shared that this was because PHC staff were not doing entries in the NCD portal as they were expected to do. Often ASHAs would keep registers and they had the most complete information about the hypertension and diabetes patients and the CHOs relied on them.

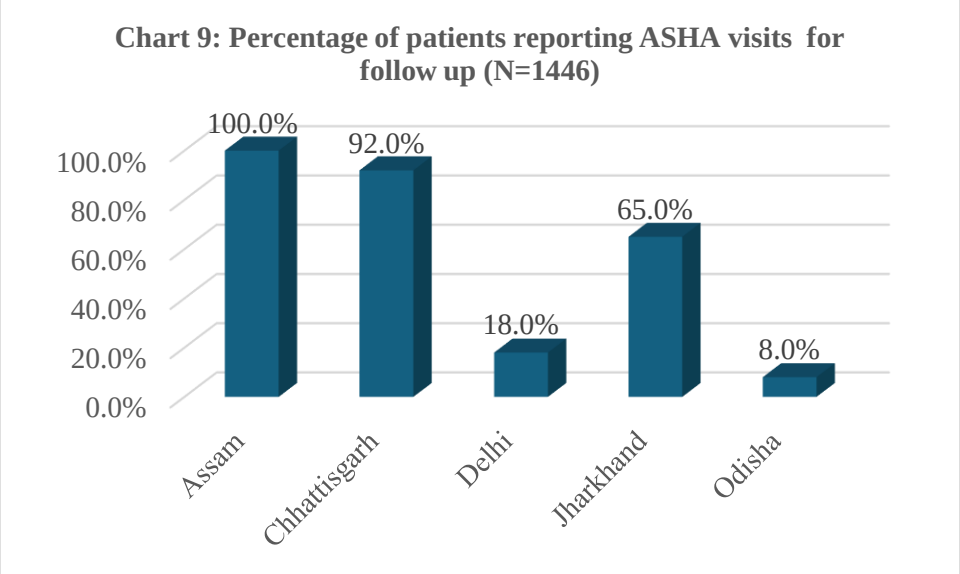
The population screening has recently been started in Delhi, and the online NCD portal does not have adequate patient data. Hence the patient data available was through opportunistic screening. In Delhi, the NCD patient data was maintained in a register at DGD Ajmeri gate. Moreover, there was only the blood sugar and blood pressure monitoring register that only had patients' names but no further details in Gali Samosan. Only the ASHAs working in the community had the data for the NCD patients. As the DGDs work on the OPD model, anyone can come and go, making screening, diagnosis, and treatment adherence a challenge.

The population screening had recently been started in Odisha, and the online NCD portal does not have adequate patient data for screened and diagnosed patients. The data available at the UPHC was based on opportunistic screening.

In Jharkhand, screening happened at the level of the VHSND with CHO and ANM attending. The CBAC form is filled for patients during the camp. Tele consultation (with doctor at the CHC) was facilitated by the CHO for patients, diagnosed with diabetes and/or hypertension

On the whole, we were able to list out approximately 4500 total registered/non registered patients of hypertension and diabetes from which the sample was derived at approximately 1/3rd of the total universe available to us.

3.27.2 Role Of ASHA in the NCD programme relevant to Diabetes and Hypertension



While Assam (100%) and Chhattisgarh(92%) did well in terms of ASHA follow-up, even in Jharkhand which otherwise had relatively less uptake from private sector, 65% said that ASHA did visit for follow up. Delhi and Odisha fared poorly which may be related to the differences between the ASHA programme between urban and rural areas. Specifically, the population norms for ASHA in urban areas is much higher at 1/1000-2500 considering the density of population but the prevalence of diabetes and hypertension is higher than rural areas.

In terms of frequency, 93% patients in Assam and Chhattisgarh said that ASHA visited twice a month or once a month for follow up. In Jharkhand too, 79% patients said ASHA visited monthly. The denominators for Delhi and Odisha were too small for analysis as most patients said ASHA did not make home visits in the first place.

With respect to the content of the discussion during the ASHA's home visits the following responses were obtained:

Table 30: Indicator which ASHA checked when she visited at home

Indicator which ASHA checked when she visited at home (N=824)	Response (%)
Compliance to medical treatment	83
Life style modification – change in diets	66
Measuring the blood pressure/ blood glucose	43
Life style modification- physical activity	24
Life style modification- substance use	15
Referral to MO nurse or doctor in case of any complications	6
Others	4
ASHA did not come to visit the house	1

It is heartening to find the ASHAs performing relatively well with respect to follow-up of NCD patients perhaps reflective of the fact that it is a recent programme and there has been a high focus on it since its introduction from the central and state government health ministries/departments. These findings, however, introduce a trend that is consistent with findings in other sections where the focus of treatment is on medication, followed by a reducing focus on diet, physical exercise and substance abuse.

ASHAs serve as an important link between CHOs and patients which is important for TA in terms of patient tracking and follow-up. An attempt was made to compare responses of ASHAs in different states through FGDs and general state study team observations to understand the level of their involvement in hypertension and diabetes treatment.

In Jharkhand, the responses of the ASHAs were well articulated and they felt that they played a significant role in following up with patients and motivating them. This needs to be considered alongside the patient interview findings where Jharkhand showed the highest dependence on the private sector for hypertension and diabetes medicines.

In Chhattisgarh, ASHAs had a good understanding and clarity of NCD programme and their responsibilities on hypertension and diabetes. ASHAs had an excellent knowledge of their patients; every ASHA knew the number of hypertension and diabetes patients in her area, irrespective if they were going to public or private sector for treatment. Even when the patients were taking medicines from private health providers, their monthly BP measurements and counselling would be done by the ASHA or the ASHA would take the patient to HWC. In Chhattisgarh, CHOs too were heavily dependent on ASHA.

In Assam, the responses from ASHA were mixed. In some villages, ASHAs did not display much awareness regarding NCDs (Gobardhanpara, Khankhowa) and seemed unmotivated (Khankhowa). In others, they did share some details about screening, food advice, etc (Piazbari, Ambari).

Delhi on the other hand had poor involvement of the ASHAs in the programme as shared by the study team. The ASHAs in the Odisha FGD shared that follow up of patients is their regular activity. They also shared their challenges in making home visits such as how most adult family members are difficult to find at home together with generally one person or a child present at home, and they fail to inform their families about the ASHA's visit. Responding to the issue of counselling , some ASHA also said *"there are households who accepts us in good/true spirit and good hospitality, requesting us for counselling as we pass their doorstep, but there are many households/families who simply behave as though we are unknown persons and on-lookers"* The two Odisha patient case studies however pointed out that no follow-up had been done by ASHA.

In addition, CHOs and their rapport with ASHA also played an important role in services for hypertension and diabetes. For example, in Chhattisgarh two of the three CHOs had a good understanding with the ASHA team and used their support to reach out to patients. The third CHO was less motivated and had communication issues with the ASHA team and its effect was seen on the programme under this HWC too. In one Assam FGD, ASHAs shared that the previous CHO had played a crucial role in providing them with excellent guidance regarding additional aspects of what they must consider about a patient when conducting screening (Assam ASHA).

In general, across the states, it was felt that not enough guidance had been given to ASHA on the precise nature of messaging for diet modifications, exercise and substance abuse. Thus, they were employing their own biases and levels of information (sometimes incorrectly) to provide information or making very broad recommendations ('don't eat rice', 'don't eat non-vegetarian food') that were not contextually appropriate and needed nuance. ASHAs from across the states talked about problems with their remunerations not being commensurate with their work as well as delays in receiving their incentives.

3.27.3 Other human resources at health facility and capacity building

Generally, the staffing of CHO or Medical Officers at the facilities was satisfactory. However, in Chhattisgarh, Auxiliary Nurse Midwives (ANMs) placement was inadequate, which was also confirmed during key informant interviews. Likewise, the assignment of multi-purpose workers (MPWs) in Jharkhand's HWCs was notably deficient,

Assam

Each of the four HWCs was staffed with Community Health Officers (CHOs), one Multi-Purpose Worker (MPW), and between one to two Auxiliary Nurse Midwives (ANMs). All CHOs, ANMs, and MPWs had undergone training or induction training specific to HWC operations. Regarding specialized training, three of the four CHOs had been trained in Standard Treatment Protocols (STP), and all four had completed the induction training for HWCs.

Those patients who come to us by their own, we get a chance to screen them with measuring scale, weighing machine etc.; ASHA does those and send them to ANM, then ANM check the blood group and sugar level, then will come to me, then will go to MPW where MPW is collecting the CBAC and verifying those.- CHO Assam

Chhattisgarh

The selection of the three HWCs was based on the tenure of their Community Health Officers (CHOs), who had been in the position for some time. All three HWCs were staffed with Multi-Purpose Workers (MPWs), but only one had an Auxiliary Nurse Midwife (ANM) on an attachment posting. A significant finding in the study was the absence of even one ANM at these centres, with CHOs suggesting that, ideally, two ANMs are necessary for optimal functioning. Regarding training, all three CHOs had undergone Standard Treatment Protocol (STP) training, and two of them had also received induction training specific to HWCs.

Delhi

Each of the two DGDs had a staff of two Medical Officers (MOs), two Auxiliary Nurse Midwives (ANMs) and, in addition to one laboratory technician and one pharmacist. One MO was deputed on contract basis through the NHM and the other was recruited through the state department exam as MO in charge. In Gali Samosan there was a AYUSH counsellor as

well. The ASHA in Delhi had received generic training on NCD. As part of their overall training they have been oriented on the various health programmes and their roles and responsibilities in managing diseases that includes NCDs. The trainings are more focussed on information sharing on the programme and not on building in depth understanding of diabetes and hypertension.

Jharkhand

In all seven HWCs, one or two Auxiliary Nurse Midwives (ANMs) were assigned. However, among these seven HWCs, only one had a Multi-Purpose Worker (MPW) on staff. The training status of Community Health Officers (CHOs) in Standard Treatment Protocols (STP) and HWC induction varied. In contrast, most ANMs reported not having undergone training specific to HWC operations.

Odisha

In the Dolabedikona UPHC, there was a MO who worked there full-time. There were visiting doctors who consulted specifically for geriatric issues and ARSH clinic. There were three ANMs attached to the UPHC and there were 8 ASHAs attached to the same UPHC who worked directly with the community.

There was one lab technician and one pharmacist at the UPHC. The ASHA were trained on the Standard Treatment Protocol and were aware of their roles and responsibilities to manage the NCD programme.

3.27.4 Maintenance of records of patients diagnosed with diabetes and/or hypertension.

In Assam, a state official shared that details of patients are kept in the register by the HWC staff ASHA-wise so the patients can be tracked via respective ASHAs (Assam state rep 1). This was observed by the study team in Chhattisgarh too. Dividing the screening and other documentation of patients based on ASHA was considered an innovation in Assam (Assam state rep 2). Assam state rep 2 shared that the work of ASHA has been divided day-wise and she gets her patients accordingly for screening. He added that screening alone is not enough, and quality of screening is important so that patients also get time to understand their condition and the process associated with it (Assam state rep 2). The Assam state official shared that counselling in terms of telling patients about the risks, the importance of not missing the medicines and refilling them a day ahead, etc, in addition to keeping the tracking bag, maintaining registers, etc had helped them for TA (Assam state rep 2). . It was also mentioned by the CHO in Assam, that they "*have a record who come to us for check-up, then again goes to private clinic and get medicine from pharmacy because they do not want to take free medicine as they have less faith. We also have a record of patients who get insulin from private as insulin is not supplied here."*

In Delhi, the state official shared that dispensaries have been asked to maintain a list of NCD patients at their level. They have been given registers where the NCD information has to be regularly updated (Delhi state rep).

Two innovations for TA in Assam- Ayushmaan Medicine Jute bag/pouch for the patient to keep medicines separately for hypertension and diabetes and also, to make sure that they come for the next month.

Tracking bags at the HWC - When CHOs fill the cards, the ASHA shift the card to the next bag signifying the coming month for follow up. If it is missed out and remains at the end of the month, then ASHA's follow-up with those patients.

In Piazbari HWC area, the CHO we has started a WhatsApp group and through this group share information to everyone and those who are not in those group, they are being informed by their acquaintances or neigbours.- CHO Assam

3.28 Voices from the field

CASE STUDY: POSITIVE CASE FOR TREATMENT ADHERENCE
Supportive healthcare providers, availability and access of healthcare provider and facility Enablers : Individual initiative: regular medication, change in diet
R 6, a 50-year-old male who has had diabetes for three years, is from the Muslim community and general caste. He receives his treatment from Piazbari HWC. With a 12th-grade education, he helps with vegetable farming on his family's land. His large family includes his parents, a brother, and their respective families, totalling twelve members. His wife is a homemaker, and his children are currently in school. His annual income is between 1.5 to 2 lakhs. They live in a mud house with a tin roof and own agricultural land where they cultivate rice and vegetables. The patient, who has had diabetes for three years, was initially diagnosed at a district civil hospital after losing consciousness. His condition is linked to a genetic predisposition as well as previous unhealthy eating habits, including high-sugar, high-fat, and processed foods. Despite having two other diabetic family members, he attributed his condition to inadequate water intake and poor diet. The patient regularly visits the Piazbari Health & Wellness Centre for treatment, overcoming the initial challenges of frequently forgetting medication. He has made significant lifestyle adjustments, focusing on healthier eating and hydration. He has to travel about 6-7 kilometres by boat for his medication from HWC. He emphasized the importance of avoiding unhealthy foods and maintaining a healthy lifestyle, especially for the younger population, acknowledging the rising incidence of diabetes among those under 30 due to poor diet, stress, and lack of physical activity.

CASE STUDY: ISSUES FACED IN TREATMENT ADHERENCE
Difficulty in access to medication, issues in treatment plan communication
A 54-year-old male patient in Chhattisgarh, belonging to the OBC category and living in poverty, expressed extreme dissatisfaction with his treatment. His family's mud and tiled house was on a rough road in a corner of an otherwise affluent village. Previously, they had migrated to Raipur for construction work to make ends meet. The patient, who has both hypertension and diabetes, first learned of his conditions at an Ayurvedic hospital a decade ago but now receives treatment from the HWC. He follows up exclusively at the HWC and takes Amlodipine and metformin, although his prescription lists Enalapril and metformin. Recently, he has been taking his medication only once a day instead of the prescribed twice a day due to limited medicine availability. He and his wife have faced challenges in accessing medication, including frequent trips to the health facility, often finding the medication unavailable or the MO absent.

"In riverine (char areas) people eat salt a lot. When they eat rice, with that they will always have chilli and salt, and this is most of the people's breakfast before they go to work. Even if they eat other veggies, with that they will still take extra salt. Through our awareness we are trying to reduce the amount of salt intake and tell them to eat veggies more.: CHO- Assam

Good Practice: Setting up kitchen garden at HWC and creating awareness regarding consuming green leafy vegetable

"In the HWC, we made a kitchen garden, to bring awareness among people of the village and they learn something from that. We planted many vegetables here like cabbage, pumpkin etc. we use to distribute among people including pregnant women. We also tell people suffering from blood pressure and diabetes that they need to consume fresh green vegetables which are fresh, then only you can stay healthy. We even started distributing plants, brinjal plant etc. We see that people listen to us, whatever we say they do it carefully. In the beginning people were uncomfortable but now a change can be seen among them." CHO Assam

Role of patients support group

"There are patients who take medicine for a month and then take a break, so what I do is through the patient support group, I tend to tell them that consistency is important if you want to get better. There are patients who after getting detected takes medicine for 15 days or a month, and they come to us and ask why am I not recovering; they do not understand that this is not viral fever or cold and cough that recovery will be fast, they should understand that the process of recovery in case of NCD is long and it cannot be recovered rather can be controlled with proper medication, food habits and lifestyle. Sometimes what we do with the patient support group is, one person who has recovered, we bring him and ask him to talk, tell about his phases of recovery so that other patient learn and understand that the recovery cannot be in weeks or months rather can take years." CHO-Assam

"In the beginning there were patients who do not take medicine continuously and a gap can be seen, in that case we can track those patients through follow up card. We wait for 1-2 days even after that we do not see any response from the patient or he or she do not turn up, we ourselves visit the patient or call the patient in the given contact number if the number provided is their own. Then ASHA calls the patients, we try to counsel the patient and make him or her understand, and make him or her a part of patient support group. In case ASHA is not available, ANM or I personally do that work of ASHA." CHO -Assam

Multiple issues (quoted by MO- DGD)- medication, diet, complicated cases

"High proportion of patients are in the age category of above 60 years ,and most common is DM type 2. The approximate average for which the patients have had DM is 5 years. The patients respond well to the treatment plan that is given to them. They are able to follow the medication routine. But the patients don't follow the exercise and diet advice that they are given. They don't control their food habits. At the dispensary level, there are not many complicated, and in case there are any complications most people prefer to go to tertiary care hospitals. The complication cases that we see at the dispensary level are diabetic foot, cramps, a few cases of cataract, and at time DM retinopathy.

The cases of eye-related complications are referred to Aravind Eye Hospital. And any other type of complication is referred to Lok Nayak Hospital. Only some of the patients come back to the dispensary once they are referred to the hospital. One reason why patients continue their

medication is the fear of surgery."MO- DGD

"The treatment adherence to diet is very low among the patients in the Chandni chowk area. There is high consumption of red meat, and patients also eat sweets on a regular basis. Items like kheer are an integral part of their diet. The MO said the counselling is done for patients for controlling diet and doing exercise, but they do not listen to the healthcare *providers. The healthcare providers are not motivated enough to continue counselling as the patients don't listen to them. The patients only follow the advice given with regard to medication." – MO DGD*

"Some patients also consult the local traditional healer or pir babas. But most of the times their medication is high on steroids, making their health even worse."- MO DGD

"It is very difficult when the patients misplace their prescriptions, then it becomes difficult to keep track the history of the patients. Every time when they come back, they need to be treated as a new patient because the doctor is unaware of the history." MO- DGD

"Approximately there is only 50% treatment adherence of the patients that come to the dispensary. As there are multiple dispensaries in the area and the patients shift between them, so it is not possible to do ensure treatment adherence. Also the patients tend to lose their prescriptions so to ensure that treatment adherence and keep track of the treatment is not always possible.- MO DGD

"Majority of the patients are local street vendors in the Jama Masjid and nearby markets and put their shops on the footpaths etc. they normally sleep late as the market is open till late and get up late in the morning and that leads to worsening of the disease. Over the years the prevalence of NCD has increased and one of the major reason for this is that lifestyle of the people in the area is very bad, they don't do any kind of exercise. The consumption of beef, fried food and spicy masalas is high. They have a sedentary lifestyle. They don't have a balances diet. So much so that the children also start having body pain. "idhar bache bhi body pain ki complaints ke saath ate hai..itna (even children complaint about body pain) sedentary lifestyle hai..koi dhoop nahi milti.." They are overly dependent on medication. - MO DGD

"I spend minimum 30 minutes with the patients. During this process I do a checkup on the patient, fill out a simple card, and inform them about the follow up visit for medicines. This also includes counselling for diets and healthy lifestyle." AMN-JH

"We conduct VHND in Angandwadi every 15 days in the presence of CHO. We ask ASHA to gather people on VHND and do follow up." Patients bring a card in which every detail of the patient is filled, along with the scheduled date for the next medicine. So, we see the card, do a checkup, and simultaneously give medicines. We also ask ASHA to visit the patient's home and do follow up."- ANM-JH

"We do face challenges due to the unavailability of medicines. We don't get medicine as per demand. Patients usually quarrel when they don't get medicines." - ANM-JH

Multiple issues (quoted by CHO-JH)- medication, diet, complicated cases

"Most sugar patients avail themselves of medicine and treatment at private facilities"- CHO JH

"The footfall at HWC is low as there is a limited supply of medicine for diabetic and hypertensive patients."- CHO JH

"The HWC covers almost 13 villages and patients need to travel approximately 4 kilometres to reach the facility. Many patients who live too far away obtain their medications from neighbouring government health facilities or private health care providers"- CHO JH

"The patient doesn't cooperate and gets irritated with us when they return without getting medicine due to the unavailability of drugs in the centre. So, the continuity to treatment is broken since they stop taking drugs from the centre."

"There is a lack of availability of drugs. As per the indent requirement of medicine, we don't receive adequate quantity of medicine. As per the previous indent, we asked for 1500 medicines and received just 1000. We lack sufficient HR because we have few ANM and no lab technicians. "

"The faraway patients who are diagnosed are not able to come to the centre. Others face problems due to medicine's unavailability."

"The people who approach the UPHC and DHH are in general poor people. Like rikshaw person, daily wage labourers. For NCD they are taking medicine for the sake of taking but do not really believe that its effective. -ANM OD

"One way of identifying non adherence by patients is when in their test the results are higher than the last time". – ANM OD

Good practice

"People in the UPHC area are mostly daily wage workers and they are highly dependent on substances and use of tobacco is very high. They start very young, as children only. The MO discussed about his initiative called Parivartan. Due to lack of deaddiction, they created this space for young adolescent." MO OD

"NCD diseases are very important. We have been demanding that OOPE in NCD is high and how the service delivery should be expanded, it is due to not having dedicated staff for NCD. GoI releases funds for the state but the manpower is through NHM sanctions. That does not happen. Only a few districts in the state have a dedicated NCD staff from the centre and they are mainly entry related. More than 5000 HWC in CG. More than 80 percent has CHO appointed. They work in periphery but have difficulty in CHC and DH." – State representative CG

"People with very high BP needing referral and services for that, ECG, CT scan are not available in CHC Ghumka. High sugar patients need HbA1c which CHC Ghumka doesn't have. However Glucose Tolerance Test (GTT) test is there in Ghumka." CHO CG

Quotes by ASHA CG

"People with BP, sugar do not take the condition seriously until they start seeing serious symptoms."

"A patient couple who are very old and live far off (relative to other bastis which are right next to the HWC). They are not able to come to take medicines and not follow treatment."

"A case of "nas dhare". The patient didn't go to the doctor despite advice and motivated. And then paralysis happened. Noe that patient comes to HWC regularly."

4. Conclusions and Recommendations

The study is successful in bringing out contextual differences affecting treatment adherence since each site offers a specific and unique set of circumstances with respect to health systems functioning, health seeking behaviour, access to drugs and diagnostics, costs, functioning of the ASHA programme etc that affect treatment adherence. These are summarized in the 'at a glance table' as well as discussed below.

Table 31: Site specific data at a glance for select indicators

Indicators	Dhubri Assam	Rajnandgaon Chhattisgarh	Central Delhi Delhi	Ranchi Jharkhand	Puri Odisha	Total
Caste						
General	309 (100%)	10 (4%)	70 (23%)	45 (15%)	201 (78%)	644 (44%)
OBC	0 (0%)	232 (84%)	57 (19%)	157 (52%)	45 (17%)	491 (34%)
SC	0 (0%)	21 (8%)	9 (3%)	12 (4%)	11 (4%)	53 (4%)
ST	0 (0%)	14 (5%)	0 (0%)	89 (29%)	1 (0%)	104 (7%)
Other /no response	0 (0%)	0 (0%)	63 (21%)	0 (0%)	3 (1%)	66 (4%)
Don't know	0 (0%)	0 (0%)	99 (33%)	0 (0%)	0 (0%)	99 (7%)
Religion						
Hindu	0 (0%)	271 (98%)	53 (18%)	117 (38%)	266 (97%)	707 (48%)
Muslim	309 (100%)	4 (1%)	244 (81%)	107 (35%)	1 (0%)	665 (45%)
Christian	0 (0%)	0 (0%)	0 (0%)	18 (6%)	6 (2%)	25 (2%)
Annual Income						
Less than 50,000	127 (41%)	160 (59%)	23 (8%)	69 (23%)	31 (11%)	410 (28%)
50,000-1,00,000	67 (22%)	85 (31%)	50 (17%)	120 (39%)	73 (27%)	395 (27%)
1,00,000-1,50,000	54 (17%)	17 (6%)	57 (19%)	61 (20%)	113 (41%)	302 (21%)
1,50,000-2,00,000	39 (13%)	3 (1%)	16 (5%)	33 (11%)	50 (18%)	141 (10%)
Prefer not to say	0 (0%)	0 (0%)	131 (44%)	1 (0%)	0 (0%)	132 (9%)
2,00,000-2,50,000	18 (6%)	2 (1%)	8 (3%)	3 (1%)	3 (1%)	34 (2%)
Above 2,50,000 and others	4 (1%)	4 (1%)	16 (5%)	17 (6%)	3 (1%)	44 (3%)
Educational status						
No formal education	198 (64%)	167 (60%)	121 (40%)	193 (63%)	78 (29%)	757 (52%)

Primary education	28 (9%)	30 (11%)	28 (9%)	13 (4%)	41 (15%)	140 (10%)
Secondary	8 (3%)	35 (13%)	83 (28%)	42 (14%)	82 (30%)	250 (17%)
Higher Secondary	5 (2%)	9 (3%)	20 (7%)	29 (10%)	11 (4%)	74 (5%)
Graduate and above	2 (1%)	0	13 (4%)	18 (6%)	9 (3%)	42 (3%)
Availability of ration card	264 (86%)	272 (98%)	176 (58%)	254 (84%)	248 (91%)	1214 (83%)
Diagnosis of disease						
Disease distribution						
Hypertension	167 (54%)	172 (62%)	108 (36%)	129 (43%)	64 (23%)	640 (44%)
Diabetes	94 (30%)	36 (13%)	86 (28%)	94 (31%)	165 (60%)	475 (32%)
Both hypertension and diabetes	48 (16%)	69 (25%)	106 (35%)	71 (23%)	45 (16%)	339 (23%)
Gestational diabetes	0 (0%)	0 (0%)	2 (1%)	0 (0%)	0 (0%)	2 (0%)
Any others/any combination of the previous responses	0 (0%)	1 (0%)	1 (0%)	9 (3%)	0 (0%)	11 (1%)
Facility where first diagnosis took place						
HWC	304 (98%)	112 (40%)	-	41 (14%)	1 (0%)	458 (31%)
UPHC	4 (1%)	32 (12%)	33 (11%)	64 (22%)	59 (22%)	192 (13%)
Private hospital	-	5 (2%)	1 (0%)	3 (1%)	164 (60%)	173 (12%)
Private unregistered clinic	-	87 (31%)	67 (22%)	-	13 (5%)	167 (11%)
District Hospital	-	13 (5%)	27 (9%)	13 (4%)	34 (13%)	87 (6%)
Government dispensaries	-		75 (25%)	-	-	75 (5%)
Others	1 (1%)	29 (10%)	99 (33%)	174 (59%)	1 (0%)	304 (21%)
Information given to patients on medication, diet, physical activity, substance abuse etc. at the time of diagnosis.						
To take medication regularly / take medication	285 (92%)	255 (92%)	206 (68%)	258 (88%)	197 (73%)	1163 (80%)
To make changes in food habits and diet	148 (48%)	201 (72%)	159 (53%)	257 (87%)	131 (49%)	896 (62%)
To regularly get vitals (BP and blood glucose) monitored	190 (61%)	206 (74%)	104 (35%)	139 (47%)	36 (13%)	675 (46%)
To make lifestyle changes in exercise and others	102 (33%)	58 (21%)	29 (10%)	105 (36%)	131 (49%)	425 (29%)
To be alert to possible side effects	14 (5%)	51 (18%)	13 (4%)	8 (3%)	136 (50%)	222 (15%)
To be more alert to other health issues that may arise (like notice foot ulcers, visit doctor for other infections quickly)	4 (1%)	4 (1%)	7 (2%)	77 (26%)	99 (37%)	191 (13%)
To refrain from use of substances (alcohol, tobacco etc)	24 (8%)	75 (27%)	10 (3%)	11 (4%)	25 (9%)	145 (10%)

Not been told any of the above	0 (0%)	13 (5%)	13 (4%)	5 (2%)	0 (0%)	31 (2%)
Any others	1 (0%)	2 (1%)	16 (5%)	4 (1%)	0 (0%)	23 (2%)
Facility approached for current treatment						
Health and wellness centre	306 (99%)	236 (85%)	-	65 (22%)	3 (1%)	610 (42%)
Urban primary health centre	0 (0%)	3 (1%)	-	4 (1%)	210 (77%)	217 (15%)
Government dispensaries	-	0 (0%)	146 (48%)	-	-	146 (10%)
Private MBBS doctor	1 (0%)	4 (1%)	19 (6%)	72 (24%)	51 (19%)	147 (10%)
Others	2 (1%)	7 (3%)	6 (2%)	20 (7%)	0 (0%)	35 (2%)
Private unregistered clinic	0 (0%)	12 (4%)	21 (7%)	17 (6%)	2 (1%)	52 (4%)
Private pharmacy/Medical shop	0 (0%)	11 (4%)	25 (8%)	25 (8%)	0	61 (4%)
Mohalla clinic	0 (0%)	-	15 (5%)	-	-	15 (1%)
District Hospital	0 (0%)	1 (0%)	6 (2%)	2 (1%)	8 (3%)	17 (1%)
Other responses/combination of responses	0 (0%)	4 (1%)	45 (15%)	60 (21%)	0 (0%)	109 (7%)
Not taking any treatment	0 (0%)	0 (0%)	0 (0%)	31 (10%)	0 (0%)	31 (2%)
Tertiary hospitals	0 (0%)	0 (0%)	20 (7%)	0 (0%)	0 (0%)	20 (1%)
Health facility visited for follow up including diagnostics.						
HWC	276 (89%)	235 (85%)	-	83 (33%)	-	594 (42%)
MO at health and wellness centre/Urban primary health centre	23 (7%)	6 (2%)	-	18 (7%)	199 (74%)	246 (18%)
Government Dispensaries MO/Mohalla clinic	-	-	142 (48%)	-	-	142 (10%)
Do not go anywhere	1 (0%)	12 (4%)	80 (27%)	21 (8%)	2 (1%)	116 (8%)
Private MBBS doctor	1 (0%)	1 (0%)	13 (4%)	43 (17%)	52 (19%)	110 (8%)
Private unregistered medical practitioner	0 (0%)	9 (3%)	13 (4%)	0 (0%)	0 (0%)	22 (2%)
HWC and private clinic	0 (0%)	0 (0%)	0 (0%)	39 (15%)	0 (0%)	39 (3%)
Private pharmacist/ Medical shop	0 (0%)	0 (0%)	0 (0%)	13 (5%)	0 (0%)	13 (1%)
Others	8 (2%)	14 (5%)	45 (15%)	37 (14%)	15 (6%)	119 (8%)
Adherence to taking medicine in the previous one week						
Don't remember (for one or more	3 (1%)	4 (1%)	9 (3%)	0	0	16

days)				(0%)	(0%)	(1%)
Missed all seven days/did not take	11 (4%)	16 (6%)	4 (1%)	29 (12%)	1 (0%)	61 (4%)
Missed six days	0 (0%)	0 (0%)	0 (0%)	1 (0%)	0 (0%)	1 (0%)
Missed five days	5 (2%)	2 (1%)	4 (1%)	1 (0%)	0 (0%)	12 (1%)
Missed four days	12 (4%)	8 (3%)	4 (1%)	6 (2%)	1 (0%)	31 (2%)
Missed three days	13 (4%)	10 (4%)	13 (4%)	1 (0%)	4 (2%)	41 (3%)
Missed two days	7 (2%)	5 (2%)	19 (7%)	2 (1%)	19 (7%)	52 (4%)
Missed one day	13 (4%)	7 (3%)	19 (7%)	3 (1%)	8 (3%)	50 (4%)
Did not miss any day	242 (79%)	215 (81%)	220 (75%)	208 (83%)	224 (87%)	1109 (81%)
Facility from where medication is being received at present						
Health and wellness centre /Urban primary health centre	307 (99.3%)	236 (84.9%)	-	64 (21.8%)	204 (75.3%)	811 (55.9%)
Private pharmacy/Medical shop	1 (0.32%)	20 (7.2%)	65 (21.6%)	131 (45%)	18 (6.7%)	235 (16.2%)
Government Dispensaries	-	-	145 (48.3%)	-	1 (0.4%)	146 (10.1%)
Private hospital	-	3 (1.0%)	16 (5.3%)	10 (3.4%)	40 (14.7%)	69 (4.8%)
Other	-	11 (4.0%)	32 (10.7%)	77 (26.2%)	1 (0.4%)	121 (8.3%)
Mohalla Clinic	-	-	15 (5%)	-	-	15 (1%)
District hospital	-	1 (0.35%)	4 (1.3%)	1 (0.3%)	6 (2.2%)	12 (0.8%)
Unregistered medical practitioner	-	6 (2.15%)	9 (3%)	2 (0.6%)	-	17 (1.2%)
Any Combination of previous responses	1 (0.32%)	1 (0.35%)	14 (4.6%)	8 (2.7%)	1 (0.3%)	25 (1.7%)
Availability of medicines at the health centres being routinely used.						
Always available	219 (71%)	247 (89%)	246 (82%)	119 (50%)	113 (43%)	944 (68%)
Mostly available (75% of the time)	88 (29%)	3 (1%)	36 (12%)	45 (19%)	113 (43%)	285 (21%)
Other	0 (0%)	21 (8%)	10 (3%)	63 (26%)	2 (1%)	96 (7%)
Available 50% of the time	1 (0%)	3 (1%)	6 (2%)	5 (2%)	31 (12%)	46 (3%)
Rarely available (less than 50%)	0 (0%)	3 (1%)	1 (0%)	1 (0%)	6 (2%)	11 (1%)
NA	0 (0%)	0 (0%)	0 (0%)	2 (1%)	0 (0%)	2 (0%)
Time spent on getting medication (for public facilities).						
Less than half an hour	176 (57%)	187 (79%)	148 (93%)	56 (89%)	130 (64%)	697 (72%)
Half an hour to one hour	130	31	8	7	53	229

	(42%)	(13%)	(5%)	(11%)	(26%)	(24%)
One -two hours	0 (0%)	4 (2%)	3 (2%)	0 (0%)	19 (9%)	26 (3%)
Others	1 (0%)	14 (6%)	1 (1%)	0 (0%)	0 (0%)	13 (1%)
% of male and females who had Loss of workday in accessing medication						
Male	31 (23%)	3 (4%)	15 (15%)	21 (23%)	15 (13%)	85 (17%)
Female	8 (5%)	4 (7%)	11 (5%)	38 (23%)	17 (11%)	88 (10%)
Patients who have approached any other healthcare providers besides the government health system	7 (2.3%)	50 (18.2%)	128 (42.7%)	114 (53.8%)	61 (24.2%)	360 (26.8%)
Insulin users across states (N only)	1 (5.3%)	1 (5.3%)	12 (63%)	2 (10.5%)	3 (15.8%)	19 (4%)
Out of Pocket Expenditure (OOPE)						
Expenditure on medication						
Never	302 (98%)	237 (86%)	186 (63%)	76 (29%)	163 (60%)	964 (68%)
Rarely	4 (1%)	3 (1%)	3 (1%)	4 (2%)	6 (2%)	20 (1%)
Sometimes	0 (0%)	7 (3%)	11 (4%)	11 (4%)	28 (10%)	57 (4%)
Most of the time	0 (0%)	0 (0%)	0 (0%)	3 (1%)	21 (8%)	24 (2%)
All the time	1 (0%)	29 (11%)	97 (33%)	160 (62%)	52 (19%)	339 (24%)
NA	0 (0%)	0 (0%)	0 (0%)	6 (2%)	0 (0%)	6
Details of Out of pocket expenditure						
Nothing	305 (99%)	188 (69%)	148 (49%)	72 (28%)	113 (49%)	826 (61%)
Travel	1 (0%)	55 (20%)	59 (20%)	97 (38%)	63 (27%)	275 (20%)
Lab testing	0 (0%)	0 (0%)	37 (12%)	2 (1%)	39 (17%)	78 (6%)
Medication	2 (1%)	35 (13%)	109 (36%)	177 (70%)	107 (46%)	430 (32%)
Consultation	0 (0%)	2 (1%)	1 (0%)	7 (3%)	47 (20%)	57 (4%)
Injection/Insulin/supplements/ others/hospitalisation	0 (0%)	2 (0%)	16 (5%)	1 (0%)	8 (3%)	27 (2%)
Average OOPE in a month (for those who spent any money)	**2675**	**104**	**763**	**535**	**2075**	877
Patients reporting ASHA visits for follow up	308 (100%)	255 (92%)	53 (18%)	195 (65%)	20 (8%)	831 (57%)

Issues in Rural Areas

Overall, the proportion of patients that took medicine daily for the week preceding the survey stood at a high 81%. The study clearly demonstrates that the HWCs are fully able to conduct the NCD programme relevant to DM and HT well at primary level provided there is proper health sector governance, as exemplified very convincingly by the case of Assam where there is a near-100% utilization of HWC services with high TA and low OOPEs at one of the HWCs. However, even within Assam, the theoretical sample of the poorer performing HWC with specific challenges of access (Khankhowa) clearly demonstrates the poorer outcomes on access to medicines and thus on TA. Even for the well-functioning HWC (Piazbari), the data on medicines being always available could be improved from 71% and saturation was not complete at the time of the study with certain households/hamlets getting left out for geographical and/or social reasons. These included vulnerable individuals such as the elderly as well as specific categories of patients such as those needing insulin or special care for complications such as dialysis.

Despite being in a similar rural area, the HWCs of Jharkhand perform poorly in stark comparison on every indicator; diagnosis at the HWC (14%), follow up at HWC (22%), availability of medicines (50%) and taking medicines from the HWC (22%). The net result on treatment adherence remains more or less the same, however, coexisting with high utilization of private services as well as high frequency of OOPEs specially on medicines and travel.

Significantly, the ASHA/Sahiyya/Mitanin programme manages to circumvent the problems affecting the HWCs, if any, and out-performs the facilities at the level of the community in the same context. Thus, even in the relatively poorly performing Jharkhand, 57% of the respondents needing assistance to understand treatment plans reported help from ASHA/ Sahiyya, 65% of respondents in Jharkhand said that ASHA visited them for follow up of which 79% patients said ASHA visited monthly. In the better-performing rural areas the ASHA programme also did expectedly well. On the whole, the ASHA programme was found to contribute very significantly to enabling TA by maintaining lists and records, counselling patients, assisting in understanding treatment options and facilitating follow-up.

The well-functioning public sector services appear to outperform the private sector amongst all sites in terms of ease of access, waiting times and availability of drugs as well as significantly on OOPE as expected. Wherever decent public health services are available, evidence suggests that people opt to avail them – as exemplified by the mix of private and public services being used in the sites other than Assam. Even in Jharkhand where the dependency on private sector is high, many more people use the HWC for BP and BS testing than do for treatment, simply because the latter is not as available, with 58% of patients getting their blood pressure test done monthly at the HWC as compared to 28% taking medicines from the same.

Issues in Urban Areas

The urban scenario needs also to be clearly articulated with the differences and similarities between Delhi and Odisha offering significant insights. Clearly, Odisha – being more ‘rural’ than the metropolis of Delhi, finds a greater reliance on the public systems and the NHM. Thus, interestingly, it is New Delhi that demonstrates more of a gap in systems than Puri. It is also noted, perhaps since the UPHC is manned by doctors, that the study finds a higher focus on medical complications in Odisha as compared to the rural contexts; something the rural facilities might take up as a gap area.

The dispensaries and mohalla clinics do a fair job in Delhi for most parameters barring follow up and documentation, where it is clear that patients are very much left to their own devices.

The multiplicity of agencies being used without any systematic connect in urban areas, combined with the fact that dispensaries or mohalla clinics are not envisaged as primary health care centres leads to the lack of data, lists, contact information, follow up information, prescription information etc which makes it difficult to even examine treatment adherence leave alone manage it. This is further exacerbated by the relative lack of community engagement because of paucity of ASHAs.

TA for Pharmaceutical Management

On the whole treatment adherence for medicines is seen to be high throughout the various contexts; which challenges the notion that people are unconcerned or careless about their disease management, provided there is some ease of access. The 'non-compliers' are affected by various factors including a lack of faith in allopathic medicines, poorer understanding of the course of the disease and its implications, treatment-fatigue and difficulties of access including distances and costs where private sector is being primarily utilized. Many of these factors apply primarily due to non-availability of public health services.

Thus, even when people broadly feel there is enough or 'decent' access to medicines, the data clearly shows that compromises are being made due to insufficient or infrequent supplies sometimes leading to the need to purchase from the private sector. The need to purchase medicines; in turn, emerges as the primary reason for OOPE and a major factor for non-adherence to medication. The links between utilization of the private sector and OOPE is clear from the study and the link between OOPE and failure to adhere to treatment is also well elucidated, especially from the qualitative findings. While treatment adherence is being maintained at about 80% across all sites barring Delhi, this at some cost of OOPEs on medicines and travel. If this indicator is to be improved, the public health systems would need to be improved for basic NCD services.

While understanding the status and factors related to pharmaceutical management and treatment adherence, special reference is needed for insulin takers. The study demonstrates that the public health systems are not making full use of the insulin availability within the systems by not requisitioning it. Supply side issues are impacting patient behaviour and compliance and significantly adding to OOPE. There is also no action to facilitate insulin storage facilities for households that are unlikely to possess refrigerators, through community action.

TA in The Private Sector

The sites of Jharkhand and Delhi demonstrate the outcomes of high utilization of the private sector with consequent OOPEs and poorer TA. Where follow up is concerned, there is a distinct advantage in *rural well-functioning public* health systems as compared to urban and / or the private sector. This is best demonstrated in Jharkhand by the lack of records and prescriptions described in the section on prescription analysis. However, even the best functioning rural HWCs are not necessarily focused on achieving follow up with patients taking care from the private sector, with certain communities getting left out from registration as well as follow up due to geographical or social marginalization.

Nonetheless, the challenge of urban areas is much greater. Communities in urban areas exhibit far less social cohesion, combined with high population density, high prevalence of NCDs and being less physically accessible to health care workers on account of traveling out for wage work. This combined with an inadequately fleshed-out primary health care system for urban areas makes for a higher risk for treatment non-adherence. The issues of continuity

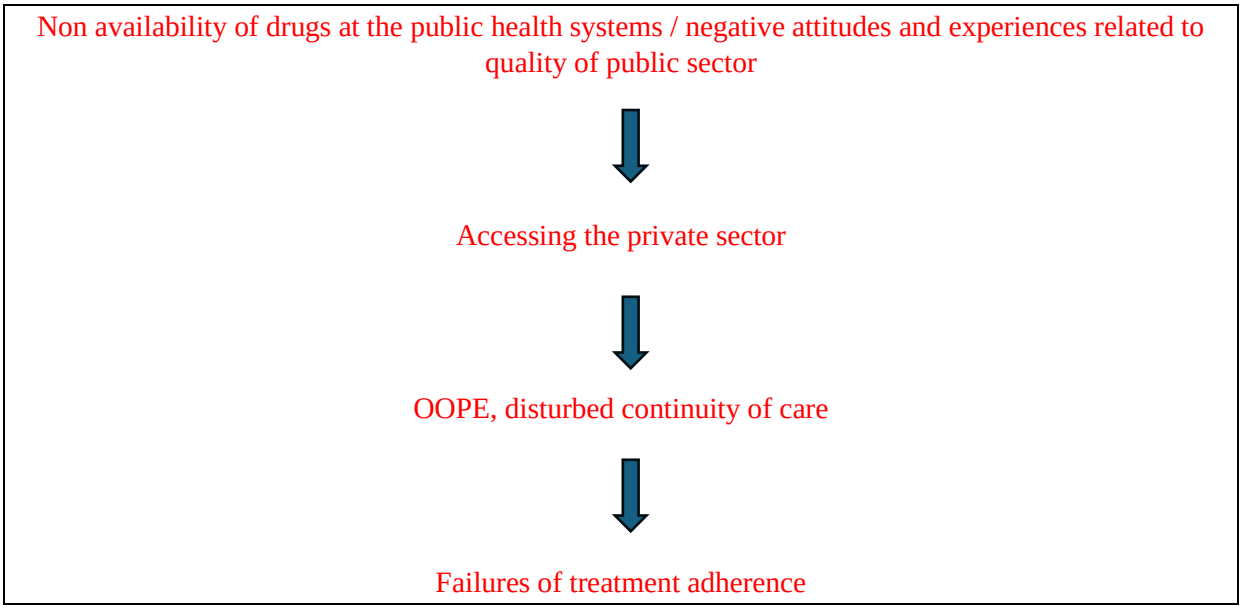
of care are demonstrated throughout the study by the challenges of getting a patient list in the first place for Odisha and Delhi detailed in the methods section, the lack of records and prescription data and the data on follow up by ASHA.

Overall, it is very important to note that from the evidence that hardly any patient behaves exclusively as a 'public' or 'private' patient and a mix of these services are used fluidly depending on circumstances and a multiplicity of factors. Clearly, this complex health seeking behaviour relates to access and quality with respect to the public health systems, as well as attitudes to the same related to previous experience. The 'lack of trust' is bidirectional with public health systems perceiving (despite evidence to the contrary) that patients are 'uncooperative' while patients perceive poorly functioning public health facilities as not worth their time with no guarantees of service, as clear from many of the case studies about patients opting for private services albeit at greater cost. However, a high degree of community participation and satisfaction with services was also observed in the immediate areas surrounding the well-functioning HWC of Piazbari, which serves to establish the point.

Considering that patients cannot be neatly classified as 'public' or 'private', community-based services thus need to take a population-based approach and cover all households, capture information on all households and follow up with all households with patients, regardless of the choices of service providers being made. In the better functioning HWC services of Assam, this is already the practice to a large extent, though unregistered families with patients taking treatment from private providers were found even in the catchment area of Piazbari – the best functioning HWC. Thus, direction needs to be given explicitly for this.

Overall, the links between guaranteed and high quality services in the public sector, the utilization of the private sector, OOPEs and treatment adherence are clearly demonstrable by the study as represented below.

A Conceptual Framework for TA Failures Arising from the Study



Issues for Non-Pharmaceutical Management Adherence

Special mention is needed on the non-pharmaceutical management of the two NCDs under consideration. While most patients across all contexts are able to identify advice related to diets, fewer mention exercise and even fewer mention substance abuse. This was also reiterated by the findings from the ASHAs. The study did not find much reference to millets

and specific instructions related to increasing fruits and vegetables in the overall diet. There was a near complete absence of a community-based approach to enable interventions such as community gardens, nutrition sensitive agriculture etc.

Considering that 'wellness' is an essential part of the functioning of the HWCs, adherence to non-pharmaceutical ancillary measures for better control needs more effort and prioritization from the health systems. It also needs a more community-based approach to organize requisite resources (such as kitchen gardens, community gyms in urban areas, basic equipment, play grounds, posters and banners etc.) for which specific capacity building on Participatory Learning and Action methods might be required. Other than that, policy interventions are required to curb the advertising and promotion of high fat sugar and salt foods (HFSS) through warning labels as Front of Pack Labels (FOPL), and strict enforcement of tobacco control measures, consideration of regulatory measures for alcohol restriction alongside the more effective community mobilization for the same.

Even with respect to messaging on diets, more nuanced information is needed that is context specific rather than broad impractical messages such as 'don't eat rice' and 'don't eat meat' observed during the study. On the whole, specific directions and capacity building is required for the social determinants of diabetes and hypertension. Planning of the wellness activities could be a good starting point and could be better enabled by the state and national resource pool available with the Ministry through specific guidelines and resource material.

Issues of the Specially Vulnerable and Left-out Households

It is clear from the study that the elderly need specific attention to enable better treatment adherence. This involves providing support for transport to the HWCs (access to wheelchairs and comfortable footpaths) as well as facilitation of accompaniment for those living alone. It also requires specific measures to help with remembering to take medication daily through day-designated pill boxes etc. that could work for people that do not read and write.

Marginalisation in terms of poorer registration due to geographical reasons and being insulin takers has also been referred to above.

The **key recommendations** arising from the study are as follows:

1. Since the availability of well-functioning HWCs comes up as the most important and primary factor enabling treatment adherence, governance of the NHM programme emerges as the single most important factor.
2. Clear direction needs to be given to reinforce the population-level coverage of the programme with constant effort to identify those that are being left out of registration, regardless of individual choices of service provider. Specific direction and focus needs to be given to register private sector users within the public health system in a more systematic manner though it was found to be happening in some HWCs already.
3. Even within well-functioning HWCs, and for all HWCs; specific direction is required to 'reach the last mile' of households getting left out for geographical or social reasons and to do that not last, but first. This will require specific instruction, action plans, effort and monitoring.
4. Supply side issues for medicines; adequate quantities and frequency need to be monitored more closely for even better treatment adherence on a daily basis.
5. With the HWCs, special attention is needed to enable regular insulin supplies and create mechanisms such as utilizing community commons for storage. Skills for use of insulin need to be enhanced as well creating community volunteers for assistance to the elderly and disabled persons unable to manage injections.

6. Urban areas experience a specific challenge for monitoring and follow-up. This cannot be achieved without hub and spoke models and full-fledged primary health care systems at the level of the community. Dispensaries and mohalla clinics need a full up-gradation to cover the entire primary care requirements of diabetes and hypertension before treatment adherence can be even examined or evaluated.
7. ASHA programme needs to be fully implemented in urban areas to enable TA considering the complexity and multiplicity of factors affecting TA at household level.

   Notable, the interventions above could significantly bring down OOPEs and enhance TA related to diabetes and hypertension.

8. Special effort is needed to provide access for the elderly in every community and enable TA. Interventions such as the provision of a better path, wheelchairs at the HWC and mobilising village youth volunteers that could help the elderly with coordination as well as transport, need to be facilitated by the primary health care teams.

9. Specific interventions need to be planned to enable PLA on social determinants of NCDs; namely diet, exercise and substance abuse. Wellness activities could be a good starting point but need to include community-based action towards creating community resources alongside behaviour change at an individual level. NGOs with skills in these areas may be employed to showcase models for this.

10. The lack of trust between community and public health systems being a bidirectional issue, requires a ‘systems’ understanding of health seeking behaviour by the health care providers. The results of this study can help the process of appreciating that patients do take responsibility for their own care if circumstances permit; and appreciate and use government services if they find them helpful and effective. Breaking through previous negative experiences by the community would also need a process of re-establishment of trust (for instance in the case of Jharkhand) which is enabled by processes such as exposure visits to the HWCs by community groups: school children, SHGs etc to appreciate it as a community resource.

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Annexures: Tools for data collection

Area mapping

Block/Ward profile: Things to check out/document when visiting the Block/Urban Ward (study location) – through observations, short talks with people in the area, informal interaction during KII, secondary literature

Demography

- Population
- Social/caste groups/ sub castes
- Urban-Rural proportion

Geography/topography

Economic status

- Kinds of occupation people are involved in
- Profile of housing– pucca, kuchha, flats, tents, street dwellers
- Specific vulnerabilities

Infrastructure

- Position within the district/city
- Availability of public transport (including railways)
- Nature of private transport – cars, bikes, cycles etc.
- Nature of roads
- Availability of electricity
- Nature of market places
- Kinds of shops
- Primary, secondary and high schools, colleges, university, polytechnics
- De-addiction and tobacco cessation centres

Health and nutrition specific

- Availability of junk food
- Nature of restaurants
- Availability of exercise spaces/gym
- Medicine shops: specific probe availability of insulin, dipsticks for urine testing, home testing kits etc
- Unregistered medical practitioners
- Traditional/informal healers
- Private hospital/clinic

Health facilities

PHCs

- Number of PHCs/ urban clinics
- How many PHCs/urban clinics without MO

HSCs/Urban Clinics

- Number of HSCs in block/ward
- How many HSCs are without ANMs

- Number of ASHAs

HWCs

- Number of HWCs
- How many have CHOs and how many don’t

CHC

- General availability of doctors and specialists
- Availability of MD Medicine specialist
- Do C-sections take place in the CHC (proxy indicator of level of functioning)

Gender

- Women’s mobility/visibility

Participant Information Sheet

Public Health Resource Society (PHRS), with support from National Health Systems Resource Centre, is conducting a study "to determine the factors affecting treatment adherence for Hypertension and Diabetes in different contexts."

We invite you to participate in this study as a respondent. A copy of the consent form will be shared with you.

I am _____ and we are undertaking a study to understand the prevalence of treatment adherence for hypertension and diabetes in different contexts.

Purpose of this study: The study aims to understand and describe the enablers and barriers affecting treatment adherence among patients diagnosed with diabetes and/or hypertension at health facilities in selected study sites. This will help assess the proportion of people not being able to comply with treatment within varying contexts. The study will examine the implementation of interventions planned for treatment adherence under the universal screening of non-communicable diseases. It will also help formulate recommendations to improve treatment adherence to hypertension and diabetes.

Procedure/methods of the study: In this context, I want to talk to you about your treatment plan and its practice. I want to get an understanding about your disease and what has been communicated to you. I also want to get a sense of your treatment plan and how you practice it and what has been your experience of coping with the disease and the treatment plan.

Are there benefits to be expected from the research to you or to others?: This research is not designed in a way where it will lead to any personal benefits. We hope that from this study we will be able to make recommendations for improvements in systems and support services.

We will also provide information to you through pictorial pamphlets about the disease, healthy diet and lifestyle changes.

In case you are suffering from a medical emergency or need urgent medical care, you will be referred to the health workers concerned, and the health authorities will be notified.

Are there any risks expected from the study to you? : The study does not involve any invasive procedure; hence there will be minimal risks. It includes individual and facility survey, a few interviews with the community and the frontline workers as well as with healthcare workers and officials. Participants will be treated with respect and dignity

Freedom to withdraw from the study at any time during the study period: You will be interviewed for around 60 minutes. You can withdraw from the study at any time during the interview. Your decision to participate in the study is voluntary, and if you decide not to participate in the study, your decision will not affect the care that otherwise you are entitled to.

Maintenance of confidentiality of records: Your individual study records will be kept confidential and your personal identity as well as your individual results will not be revealed to anybody or in any publication. During publication, the data will be presented in an aggregate form only and your individual data will not be disclosed.

Possible current and future uses of the data to be generated from the research: Your identity will be kept anonymous and confidential, but information shared by you will be used in the study and any further publication. The results of the study will be shared with appropriate authorities for planning healthcare services which will be beneficial in the future.

We will use the information that you have given us only for the purpose of the aforementioned study, i.e. in order to understand the determinants of treatment adherence. Your information will be securely stored in password protected files with the PHRS. You have the right to ask us about how we are using the data.

In case of more queries or information regarding the study, you can contact:

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Informed Consent Form

Title of the research study: Prevalence of treatment adherence for hypertension and diabetes in different contexts.

Name of the organisation: Public Health Resource Society

Name of the Principal Investigator: Dr. Vandana Prasad and Dr. Sulakshana Nandi

The study aims to understand and describe the enablers and barriers affecting treatment adherence among patients diagnosed with diabetes and/or hypertension at health facilities in selected study sites.

The study details have been provided to me in writing and explained to me in my own language. I confirm that I have understood the above research study and had the opportunity to ask questions. I understand that my participation in the study is voluntary and that I am free to withdraw at any time without giving any reason. My decision to withdraw will not affect the care that otherwise I am entitled to.

I understand that my identity will be kept anonymous and confidential during the research period, after its completion as well as during the publication of the results. I am aware that information shared by me will be used in the study and any further publication.

I have been given a copy of the information sheet giving details of the study. I volunteer to participate in the above-mentioned study. By signing this consent form, I attest that the information given in this document is true to my knowledge.

I give consent to record the interview Yes No

I give consent to take pictures of prescription, medicine etc Yes No

Name of the respondent Signature / thumb impression of the respondent

Name of the witness Signature / thumb impression of the witness

Date:

Field Investigator certificate:

I certify that all the elements including the nature, purpose and possible risk of the above study have been fully explained to the participant. In my judgment, the participant possesses the legal capacity to give informed consent to participate in this research and is voluntarily and knowingly giving informed consent to participate.

Name and signature of the Field Investigator

Name: Signature:

Date:

A. Participant Profile

Patient's name: Patient id:	1.	Village /Ward name: State: City: District: Block: Para/Hamlet:
	2.	Age (mths/yrs): ☐☐
Contact details (phone no.):	3.	Gender: Male/Female/Transgender/Other_____

	B. GENERAL & HOUSEHOLD INFORMATION					
SI No.		**OPTIONS**			**Tick/circle the appropriate**	
1.	Have you always lived in this village/ward	Yes				
		No				
1b.	How many years have you stayed in your current place?					
2.	In the last one year, did you stay outside your home for more than a month? *(Probe – times when migration has occurred for longer than a month)*		**Purpose of migration**	**Duration (days/ months)**	**Place where (migrated from)**	**Place (migrated to)**
3	Religion	Hindu				
		Muslim				

		Christian		
		Sikh		
		Buddhist		
		Jain		
		Adivasi Religion		
		Other (Please specify)		
		Don’t follow any religion		
		Don’t know		
		No response/prefer not to say		
4.	Caste/Category	General		
		Schedule caste		
		Schedule tribe		
		Other backward classes		
		Write name of the caste		
		Don’t know		
		No response/prefer not to say		
			Tick which occupation	
5.	What work do you do?/ What is your occupation? ~~Occupational activity –~~ multiple choices – (meant for the participant) - *Circle the occupational activity and write the annual income*	Self-employed agriculture work (livestock rearing, fishing, farming, forest work)	1	
		Daily wage non-agriculture work (construction work, factory work, mason, driver)	2	
		Self-employed non-agriculture work (transport business, shopkeeper, etc)	3	
		Daily wage agriculture work (fishing, farming, forest work, livestock rearing)	4	
		Unemployed	5	

		Unpaid family work (housewife)	6	
		Salaried in government or private job	7	
		Government grassroots workers (eg. AWW, ASHA worker, Rozgar sahayak etc.)	8	
		Don't know	9	
		No response/prefer not to say	10	
6.	Family's Annual Income	Less than 50,000 50,000-1,00,000 1,00,000-1,50,000 1,50,000-2,00,000 2,00,000-2,50,000 2,50,000-3,00,000 3,00,000-3,50,000 3,50,000-4,00,000 More than 4,00,000		
7.	Types of Houses (The investigator has to inspect the house and surround it properly)	Earthen house and pallet roof Mud house and asbestos roof Mud house and tile roof Cemented floor/walls and thatched roof Asbestos cemented floor/wall and ceiling Cemented floor/wall and tiled roof Concrete slab house Others _____specify		
8.	Level of education (tick only the highest educational qualification)	Not gone to school		
		Not literate		
		Class 1-4		
		Passed Primary(5^{th} class)		
		Middle school (8^{th} class)		

		10th Pass	
		12th pass	
		Can sign his/her name only	
		Graduation (BA, BSc etc)	
		Post graduation (MA, MSc etc)	
		Others (please specify)	
		Don’t know	
		No response/prefer not to say	
9.	Total members in the family/ Household Size?		
Notes:			
10	Do you get subsidised ration?	Yes No If no then skip to next part	
10.b	How much grain do you get monthly per person?		
10.c	How much grain do you get monthly for whole family?		
10.d	Rate per kg of grain?		
10.e	Type of Card (name of scheme) as per physical verification done by surveyor *(Ask to see the ration card)*		

**The questions that we will be asked will pertain to the compliance with the most recent prescription or the instructions given by the healthcare provider.

I. Disease diagnosis

1. What illness do you have? (read out each of the following options) (multiple response) (Instruction to investigator if response is that person is not aware of any illness, we will go for case study and abort the interview)
    - □ Diabetes
    - □ Hypertension
    - □ Both
    - □ Gestational diabetes
    - □ Don't know
    - □ None from the above
    - □ Any others_____(Please specify)

2. How long ago did you first find out about your illness?
    …….years ago/…….months ago
3. Where did you find out that you have this illness? (tick one and write name)
    - □ Sub health centre
    - □ Health and wellness centre
    - □ Urban primary health centre
    - □ Rural PHC
    - □ Moholla clinics
    - □ Government dispensaries
    - □ District Hospital
    - □ Community Health Centre
    - □ Private hospital
    - □ Private unregistered clinic
    - □ Traditional Healer / Baga / Gunia / Bez / Ojha
    - □ Private pharmacy/Medical shop
    - □ Others (specify…….)
    - □ Health facility name …….
4. Who informed you about your illness? (tick one)
    - □ ASHA/ Mitanin / Sahiya
    - □ ANM/MPW
    - □ CHO
    - □ Nurse other than CHO
    - □ Medical officer at health and wellness center/Urban primary health center
    - □ MO at Mohalla clinic
    - □ MO at government dispensaries
    - □ Medical Officer at the Community health center
    - □ Medical officer at District hospital
    - □ Government specialist doctor
    - □ Private MBBS /MD doctor
    - □ Private unregistered medical practitioner
    - □ Traditional Healer / Baga / Gunia / Bez / Ojha Private pharmacist
    - □ Others (specify…….)
    - □ Name of the person …….

5. How did you find out that you have this illness? (tick one)
    - When I had gone to the provider on feeling sick
    - During NCD screening/testing in the village
    - During NCD screening/testing in the health facility
    - During some other disease treatment
    - During general check up
    - During pregnancy check up
    - Others (please specify)
6. Does any of your family members (previous generation or current) had/have diabetes or hypertension(This will be based on Question 2 answer)?
    - Yes
    - No
    - Not Sure
7. Where all do you go presently for your treatment? (multiple responses)
    - Sub health centre
    - Health and wellness centre
    - Urban primary health centre
    - Rural PHC
    - Mohalla clinic
    - Government dispensaries
    - District Hospital
    - Community Health Centre
    - Private MBBS doctor
    - Private unregistered clinic
    - Traditional Healer / Baga / Gunia / Bez / Ojha
    - Private pharmacy/Medical shop
    - Others (specify…….)
    - Name of the facility/location …….

II. Treatment plan communication to the patient at the time of diagnosis

8. When you were diagnosed, how long were you told you would be needing the treatment for?
    - Not told anything
    - Life long
    - As long as advised
    - For a short time
    - Till I get better
    - To keep taking till I come back for follow-up
    - Not sure
9. Were you given some written document with information about the disease? (Check for any written document and photograph it after taking consent)
    - Yes
    - No
    - Not sure
    - Other_____(Please specify)
10. Were you told that your BP/Sugar will need to be monitored regularly?
    - Yes
    - No
    - Don’t remember

11. Were you told that during the course of the disease, your medication or its dosage may need to be changed (either increased/decreased/ use of injection along with the oral methods)
    - Yes
    - No
    - Don’t remember
    - Others_____(Please specify)

12. Did the healthcare provider answer your questions/clarify your doubts about your disease?
    - Yes
    - No
    - Not everything
    - Not sure
    - Do not remember
    - Other _____(please specify)

13. What all were you told about how you can manage this disease? (first ask open ended and then probe each option) (multiple responses)

    _____
    - To take medication
    - To take medication regularly
    - To be alert to possible side effects
    - To regularly get vitals (BP and blood glucose) monitored
    - How to take medication(with water, after/before food etc)
    - To be more alert to other health issues that may arise (like notice foot ulcers, visit doctor for other infections quickly)
    - To make changes in physical activity like exercises etc
    - To make changes in food habits and diet
    - To refrain from use of substances (alcohol, tobacco etc)
    - Have not been told any of the above
    - Any others_____(please specify)

14. Who explained the process of taking the medication to you? (multiple)
    - ASHA
    - ANM
    - Community Health Officer
    - Nurse other than CHO
    - Medical officer at health and wellness center/Urban primary health center
    - Medical Officer at the Community health center
    - Medical officer at District hospital
    - Government specialist doctor
    - Mohalla Clinic MO
    - Government Dispensaries MO
    - Private MBBS doctor
    - Unregistered medical practitioner
    - Traditional Healer / Baga / Gunia / Bez / Ojha
    - Family member

- Friend
- Another patient
- Community member/neighbour
- Representative from NGO/Civil society organisation
- No one
- Not Applicable
- Other (specify…….)

15. How long did the healthcare provider spend in explaining the prescription/treatment plant to you?
    - 1-2 minutes
    - 2-5 minutes
    - 5-10 minutes
    - 10-15 minutes
    - 15-20 minutes
    - 20-30 minutes
    - More than 30 minutes
    - Not Applicable

16. Were you told what to do in case you have any side-effects from your medication?
    - Contact the ASHA
    - Contact ANM
    - Contact CHO
    - Go to the nearest health and wellness centre
    - Go to the PHC
    - Go to the CHC
    - MO at MC
    - MO at Government Dispensaries
    - Nothing was mentioned
    - Others_____(specify)
    - Not sure
    - Do not remember
    - Others _____(please specify)

********** End of initial phase section**********

III. Current treatment plan and adherence

17. Where do you currently get your medication from?
    - In the village from ASHA
    - In the village from ANM
    - Health and wellness centre (CHO)/Urban primary health centre
    - PHC
    - Mohalla Clinic
    - Government Dispensaries
    - CHC
    - District hospital
    - Private hospital
    - Unregistered medical practitioner

- Traditional Healer / Baga / Gunia / Bez / Ojha
- Private pharmacy/Medical shop
- Other……..(please specify)

18. Is the medication always available when you go to your usual health centre?(where do you get it from to be referred)
    - Always available
    - Mostly available (75% of the time)
    - Available 50% of the time
    - Rarely available (less than 50%)
    - Other

19. What medicines are you currently taking? (Request the patient to allow you to take a picture of the medicines, wherever available, after taking the consent of the patient)

Name of disease	Name of Medicine	Tablet or injection	MiliGrams (mg)	Number of tablets/injections patient takes each time	How many times a day this dose is taken

20. What is written in your prescription? (Request the patient to allow you to take a picture of the current prescription, wherever available, after taking the consent of the patient)

Name of disease	Name of Medicine	Tablet or injection	Grams	Number of tablets/injections to be taken each time	How many times a day this dose is to be taken

21. Do you think you currently taking the medication as per your current prescription?
    - Yes (skip next question)
    - No
    - Not sure
    - Other_____(please specify)

22. If not, then why not?
- Another doctor suggested something else
- Pharmacist (medical shop shopkeeper) suggested something else
- Friend suggested something else
- Family suggested something else
- Another patient suggested something else
- I read something about it and therefore changed
- Had side effect from the prescribed medicine
- That particular medicine was not available
- That medicine was not effective
- Did not have money to buy
- Other…….(specify)

23. How often do you have to get your medication?
- Daily
- Weekly
- Once a month
- Once in two months
- Once in three months
- Once in 6 months

24. How much time do you have to travel (one way) to get your medication?
- Less than half an hour
- Half an hour to 1 hour
- 1-2 hours
- 2-3 hours
- 3-4 hours
- Other _____(please specify)

25. What kind of transport do you use/ how do you travel to get your medication?
- Walk
- Shared auto/cab
- Public transport
- Others_____

26. Do you have to lose a workday to get your medicine?
- Yes
- No
- Other _____ (please specify)

27. Did you take your medicine everyday in the last 7 days? (write Yes, No or Don't remember)

Yesterday(1)	Day before (2)	Day before that (3)	Day before that (4)	Day before that (5)	Day before that (6)	Day before that (7)

*If medicine has been missed even one day, ask the next question. If No and don't remember the next question will be asked

28. What are the reasons for not being able to take your medication? (* give enough time to think, probe the options, confirm..) (If patient is unable to respond then investigator can read out the responses)
    - Unavailability of medicine at the health facility
    - Not been able to go to the health facility to replenish the medication
    - Medicine was not showing results/did not feel it was effective
    - Caused side effects
    - Forget to take medication
    - Unable to understand the prescription/instructions
    - Confusion between prescriptions from multiple healthcare providers
    - Attending wedding/family ceremony
    - Attending festivals
    - Went out of town
    - Was fasting
    - Religious ceremony
    - Was ill with something else
    - Admitted to hospital
    - Did not have money to buy
    - Other (specify…….)

29. Have you ever started taking insulin or other injections?(This will be applicable for diabetes patient)
    - Yes
    - No

    If yes, complete the insulin section and return to the next question.

IV.OOPE

30. Currently do you have to pay for the medication?
    - All the time
    - Most of time
    - Sometimes
    - Rarely
    - Never (skip next question)
31. On what all did you have to do out of pocket expenditure (Multiple responses)(*Use the options to probe)
    - Travel
    - Medication
    - Consultation
    - Lab testing
    - Injection/Insulin
    - Hospitalisation
    - Supplements
    - Nothing
    - Others_____(Please specify)

32. In a month how much money is spent on medication ?

Rs……..

IV. Attitude towards the treatment plan

33. Do you think you should continue taking the medication to control the disease?

- Yes
- No
- Not sure
- Other_____(please specify)

34. What are the issues that you face in adhering to your treatment plan? (Probe all options).

- Lack of access to services/medication
- Lack of availability to services/medication
- Lack of sensitive and understanding healthcare providers
- Emotional and mental effect of the disease
- Financial burden
- Additional responsibility
- Did not clearly understand what all needs to be done
- Increased restrictions
- Other illnesses
- Don't get time
- Migration
- I don't think I need the treatment anymore
- I don't think the treatment is effective
- I think the treatment is ineffective
- Not easy to follow the prescription
- Easy to follow/understand the treatment plan
- Others……(please specify)

VI.Practice in attending follow up visits

35. Do you do follow up visit to the medical officer/health facility?

- Yes
- No
- Not sure

36. Where do you have to go for follow- up visit?

- ASHA
- ANM/MPW
- CHO
- Nurse other than CHO
- Medical officer at health and wellness center/Urban primary health center
- Medical Officer at the Community health center
- MC Mohalla clinic
- Government Dispensaries MO
- Medical officer at District hospital
- Government specialist doctor
- Private MBBS doctor
- Private unregistered medical practitioner
- Traditional Healer / Baga / Gunia / Bez / Ojha

- Private pharmacist/ Medical shop
- Others (specify…….)
- Name of the person …….
- Do not go anywhere

37. How often do you see/consult the doctor?
- Only when feeling unwell
- When there are side effects
- Once in three months
- Once in 6 months
- Once in one year
- Only when the vital monitoring is observed in BP or sugar
- In case the medicine needs to be changed/updated
- Others_____(please specify)

VII.Monitoring of health indicators (BP, Blood glucose)

38. How often is your blood pressure taken? (if HT)(select multiple)
- Is not taken
- Monthly
- Every two months
- Every 3 months
- Twice a year
- Once a year
- Whenever I go to take the medication from the health facility

39. Where is it done?
- Sub health centre
- Health and wellness centre
- Urban primary health centre
- Rural PHC
- District Hospital
- CHC
- Mohalla clinic
- Government dispensaries
- Private clinic
- Private hospital
- Traditional Healer / Baga / Gunia / Bez / Ojha
- Home
- Is not taken
- Others (please specify…….)

40. How often is your blood glucose test done? (if DM)(select multiple)
- Is not taken
- Monthly
- Every two months
- Every 3 months
- Twice a year
- Once a year
- Whenever I go to take the medication from the health facility

41. Where is it done?

- Health and wellness centre (HWC)
- Urban primary health centre (Urban PHC)
- Rural PHC
- Moholla clinic
- Government dispensaries
- District Hospital
- CHC
- Private clinic
- Private hospital
- Traditional healer
- Home
- Is not taken
- Others (specify…….)

42. Has there been in change in your medication based on monitoring of your health indicators?
    - Yes
    - No
    - Not sure

VIII. Availability and access to NCD services at HWC/UPHC

A. Availability and access to medication at the health facility

43. Do you need any id to get your medication from the health centre?
    - Yes
    - No
    - Other_____(please specify)

44. If yes, then what id do you need to take?
    - Aadhaar
    - Ration card
    - Unique health id
    - Ayushman Card
    - State level ids…..
    - Others (specify…..)

45. If yes, What are the difficulties that you face in accessing your medication?

    *Ask each as prompt
    - Have to go multiple times to get the medication from the health facility
    - Unable to get the medication due to unavailability
    - Unable to get due to unavailability of medical officer
    - Unable to get medication in case there is change in medication
    - Loss of daily wages
    - Health care facility is far away
    - Unable to leave children at home
    - Cannot go alone to the health facility
    - Out of pocket expenditure on travel
    - Difficult to reach the health facility
    - No, do not face any problem
    - Others_____please specify

IX. Experience with health care providers

46. What is your view on how you are treated by the healthcare provider when you go to them?
    - Extremely satisfied
    - Satisfied
    - Neither satisfied nor dissatisfied
    - Dissatisfied
    - Extremely dissatisfied
    - Others _____ (please specify)
47. Are you seen by the same doctor/Healthcare provider each time you visit the health facility?
    - Yes
    - No
48. If you prefer seeing a particular/specific doctor, then what is the reason for that?
    - Explains the process clearly
    - Sensitivity
    - Listens to my health issues
    - Supports in providing information and enabling changes in diet, physical activity and substance abuse
    - Others……(specify)

X. Follow up for treatment adherence by ASHA

49. Does ASHA visit you for follow up?
    - Yes
    - No
50. If yes, then how many times did the ASHA come for home visit?
    - Monthly
    - Once in three months
    - Once in 6 months
    - Once a year
    - Never
    - Other_____(please specify)
51. If yes, then what did the ASHA ask you once she visited you at home?
    - Compliance to Treatment whether or not taking medication properly
    - Checking on diet
    - Life style modification- change in diet
    - Life style modification- physical activity
    - Life style modification- substance use)
    - Measuring the blood pressure/ blood glucose
    - Referral to MO nurse or doctor in case of any complications
    - ASHA did not come to visit the house
    - Other_____ (please specify)
52. What was the support that was provided by the ASHA?
    - Treatment adherence
    - Provide emotional support
    - Provide information about diseases
    - Raise awareness about complications
    - Countering/Coping stigma

- Enabling support for treatment continuation
- Enabling support for changes in diet
- Enabling support for doing physical activity
- Enabling support for avoiding substance abuse
- No help provided

XI.Support to patient- Patient Support group/family support

53. Are you able to understand your treatment plan/prescription on your own?
    - Yes
    - No
    - Other____(please specify)
54. If yes, then does anybody help you in understanding/ following your prescription/treatment plan?
    - Family member
    - Relatives
    - Neighbours
    - Another Doctor
    - ASHA
    - ANM
    - Friends
    - Other patient
    - NGO worker
    - Patient support group

XII. Multiple treatment plans (THIS WILL PERTAIN ONLY TO THE CURRENT PLAN)

55. Have you approached any other healthcare providers besides the government health system for treatment of your disease?
    - Yes
    - No
56. Who did you go to other than government doctor at the government health facility?
    - Private doctor
    - Faith healer
    - Unregistered medical practitioner
    - Traditional healer
    - Ayurveda or Yoga practitioner
    - Other _____(please specify)
57. Why did you approach the them? (multiple responses)
    - On advise of a relative
    - On advise of a medical officer
    - During a health emergency
    - Complications
    - Easily accessible
    - Attitude of the healthcare provider is better
    - Clarity in instructions of taking medicine
    - More effective medication
    - Trust

- Sensitive to my needs
- For better treatment of the disease
- Did not go to anyone else
- Also go to government simultaneously
- Not satisfied with the treatment at government facility
- Insensitive treatment at government facility
- Access issues at government facility
- Unavailability of doctor at government facility
- Unavailability of medication at government facility
- Registering is difficult process at government facility
- Did not have unique health id needed at government facility
- It was an emergency
- I am going to the government facility
- Other_____(please specify)

58. id the private and public health doctor prescribe different medication?
    - Yes
    - No
59. How often do you visit the private doctor/informal healer?
    - Once a month
    - Once in two months
    - Once in three months
    - Once in six months
    - Not applicable
60. Are you currently taking medicines from different people at the same time?
    - Yes
    - No
61. Why are you taking medicine from multiple healthcare providers?
    - Easier to follow
    - Gives more clarity
    - Sometimes one works better
    - People keep telling me different things

62. What would help you to take your medication better?

XIII. Lifestyle changes advised Diet

63. Have you been told anything about change in your diet/physical activity/substance use?
    - Diet
    - Physical Activity
    - Substance use
    - Not told anything
64. If yes, then what all are you able to follow(Diet, physical activity, substance use) ?

    (Multiple responses)

    - Consume a variety of fresh, seasonal and locally available fruits and vegetables
    - Eat whole cereals and pulses(with peel)

- Avoid eating food high sugar, salt and fat foods like packaged food
- Avoid salt rich foods(pickles, namkeens etc)
- Restrict intake of red meat(like mutton, liver etc)
- Consume lean meat (chicken, fish)
- Reduce consumption of deep fried foods
- Drink plenty of water
- Decrease excess amount of tea, coffee and cold drinks
- Do regular exercise
- Do moderate exercise for at least 150 minutes per week
- Do brisk walking, jogging, cycling, dancing, playing sports, yoga
- Carrying/moving moderate loads(less than 20 kg)
- Do activities that increase the heart rate
- Not required
- Exercise in groups
- Do yoga
- Choose and activity that fits into your routine
- Avoid the use of alcohol
- Avoid the use of tobacco in any form Nothing is specified
- Not sure
- Nothing mentionedAny other_____(please specify)

65. If yes, then who told you this about your diet, physical activity, substance use?(multiple responses)
    - ASHA
    - ANM/MPW
    - Community Health Officer
    - Nurse other than CHO
    - Medical officer at HWC/UPHC
    - Medical officer at CHC
    - MO at MC
    - MO at government dispensaries
    - Medical officer at district hospital
    - Friends
    - Peer support group
    - Others with same disease in the community
    - NGO worker
    - Counsellor
    - Government specialist doctor
    - Private MBBS doctor
    - Unregistered medical practitioner
    - Traditional Healer / Baga / Gunia / Bez / Ojha
    - Private pharmacist/ Medical shop
    - No one told
    - Other_____(please specify)

66. What is the reason that you are not able to follow it(diet, physical activity, substance use) ? –

- Don’t have financial resources
- It is not available
- Did not know I have to follow it
- Do not have family support
- Do not have support from peers/friends
- Not able to follow to follow it all the time
- Gym or free space, exercise space or equipment not available
- Non- Availability of public gyms
- Non- Availability of public yoga/exercise classes
- Non- Availability of parks and open spaces for walking
- Non- Availability of free yoga classes
- De-addiction services are not available
- Did not know I have to follow it
- Substances are easily available everywhere
- Others buy the substances for me (peer pressure)
- Don’t have time
- Other_____(please specify)
- Always follow

Interview Guide (ANM/CHO/MO)

The interviewer will note down the Personal and professional details of the key informat:

1. Name of respondent
2. Age
3. Sex (M/F)
4. Total work experience
5. Present Designation
6. Current location of posting
7. Number of months/years posted in current location

Situation of NCDs in the area. Ask the respondents about-

1. Their understanding of diabetes and hypertension in this area. (probe diabetes and hypertension independently in all questions)
2. Prevalence of NCD in their HWC/PHC/Urban clinic. Average number of patients suffering from diabetes and hypertension who approach the HWC/PHC/Urban clinic.
3. Farthest distance that a patient might be coming from.
4. Average wait time for a patient to be served.
5. Average time spent in the first interaction once a patient has been diagnosed.
6. Language issues in their area.
7. Ease in communication with patients and patient's ability to understand the diagnosis and treatment plan.
8. Expenditures (travel, medication, tests etc) that might be undertaken by the patients for their treatment.
9. System for continuity of care between the respondent and the ASHA/ ANM/CHO/MO/district or state manager for NCD. Probe whether a card or document is shared, or an app based system for sharing information.
10. MIS system used for monitoring and surveillance. (Request to share recent reports(ask for data if possible))
11. Record of drug related adverse effects. Monitoring and recording of any drug related adverse effects among patients.

Nature of services provided

12. Services available to patients of diabetes and hypertension at center/hospital? (probe diagnostics, treatment, prevention, promotion, rehabilitative services. Probe systems for medical care and systems for counseling – what is the HR in place, including lab services)
13. Ask for how long have the NCD services have been functional in their area.
14. SOPs/ STGs made available to health workers for DM and HT.
15. Role in diagnosing and managing diabetes and hypertension among patients, request an example/illustration.
16. Role in referral of patients with diabetes and hypertension, request to give an example/ illustration.
17. Counselling provided to patients with diabetes and hypertension.
18. Steps taken to promote healthy diet and lifestyle of patients.

Treatment adherence for diabetes and hypertension

19. Inquire about their understanding of treatment adherence among patients of diabetes and hypertension.
20. Role in ensuring treatment adherence among diabetes and hypertension patients.
21. If any training is given on how to ensure treatment adherenceand content of the training.
22. Inquire about how treatment adherence is monitored and how is a patient not taking their medicine identified.
23. Type of support from other health care workers or any community members for work on treatment adherence. (probe for ASHA, ANM, MO, CHO, SHG, women's group, VHSNC, panchayat member etc.)

Challenges and barriers

24. Challenges that you faced in provision of NCD services to patients at the health and wellness centre/hospital/health centre. (probe availability of medicines, diagnostics, equipment, adequacy of HR)
25. Inquire about how these challenges are addressed and what are their suggestions on the same.
26. Challenges/issues faced by patients in accessing NCD services at the HCW/PHC/Urban clinic.
27. Inquire about what they think could be the challenges faced by patients due to which they are unable to adhere to their treatment plan. Examples (probe at health systems, facility, community, family and individual levels)
28. Steps taken if someone does not adhere to treatment. Request them to give examples. Their suggestions on how the challenges can be addressed.
29. Suggestions on how treatment adherence can be improved among the patients in this context.
30. Suggestions on the kind of training needed to provide NCD services/respond to the patients better.
31. Any other suggestions or questions.

Facility Survey

Block Name:

HWC (SHC/PHC) Name:

Date:

SERVICES	Response	Additional information
General Information		
Population (Current)		
Cumulative screened for HTN in the past one year		
Cumulative diagnosed for HTN in the past one year		
Cumulative screened for DM in the past one year		
Cumulative diagnosed for DM in the past one year		
Availability Of Diagnostics		
No. of Tablets of Diabetes disbursed during the month		
No. of Injections of Diabetes disbursed during the month		
No. of Tablets of Hypertension disbursed during the month		
Availability of Glucometer		
Number of Glucometer strips currently available		
Number of Lancets currently available		
Availability of functional BP apparatus in HWC (YES/NO)		
Do you do hemoglobin test		

in your HWCs (Yes/No)		
If yes, by which method are you doing Hb test (Sahil's method, Digital hemoglobin meter, using litmus paper)		
HR		
Number of Medical Officer		
Number of ANM/ other nurse		
Number of MPW (Male)		
Did CHO/RMA receive training on Standard treatment protocols related to HWC? (Yes/No)		
Did CHO receive Induction training on HWC? (Yes/No)		
How many ANM received training on HWC? (Yes/No)		
How many Male MPW received training on HWC? (Yes/No)		
Any specialist doctor visiting		
Number of Lab technician		

List of Drugs to be indented by the HWC

Name of Drug	**Dosage**	**Availability**		
Antihypertensive medicines		**Quantity Indented**	**Quantity Received**	**Current Stock**
Amlodipine	Tablet 2.5 mg			
	Tablet 5 mg			
	Tablet 10 mg			
Enalapril				

	Tablet 5 mg			
Telmisartan	Tablet 40 mg			
Hydrochlorothiazide	Tablet 12.5 mg			
Hydrochlorothiazide	Tablet 25 mg			
Antidiabetic				
Glimepiride	Tablet 2 mg			
Insulin (Soluble)	Injection 40 IU/ml			
Intermediate Acting (NPH) Insulin	Injection 40 IU/ml			
Premix Insulin30:70 Injection (Regular:NPH)	Injection 40 IU/ml			
Metformin	Tablet 500 mg			
	SR Table 500 mg			
Glibenclamide	Tablet 2.5 mg			
Glibenclamide	Tablet 5mg			
Glucose Packet	75 mg for OGTT Test			

List of Drugs to be available in primary healthcare facilities in each state

Name of Drug	**Dosage**	**Quantity Indented**	**Quantity Received**	**Current Stock**
Assam				
Glimepiride	1 mg			
Odisha				
Atenolol	50mg			

Clinidipine	10mg			
Esmolol Hydrochloride	5mg			
Losartan Potassium	50mg			
Methyl Dopa	250mg			
Metoprolol Tartarate	50mg			
Metoprolol Tartarate	25mg			
Nifedipine	5mg			
Ramipril	5mg			
Chhattisgarh				
Atenolol	50mg			
Atenolol	25mg			
Enalapril	2.5mg			
Methyldopa	250mg			
Methyldopa	500mg			
Metoprolol	25mg			
Metoprolol	50mg			
Nifedipine	10mg			
Nifedipine	20mg			
Delhi				
Prazosin	2.5mg			
Prazosin	5mg			
Methyldopa	250mg			
Telmisartan	20mg			

*If any other, please list them below:

Name of Drug	Dosage	Quantity Indented	Quantity Received	Current Stock