

Voices from the Margins of Care

People Living with Noncommunicable Diseases in Asia and Africa

Global Health Advocacy Incubator
Changing Policies to Save Lives

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Acknowledgments

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The **Global Health Advocacy Incubator** (GHAI) uses the power of advocacy to tackle critical public health challenges across the globe – including food and nutrition policy, injury and overdose prevention, and building resilient and equitable health systems. We are an initiative of the **Campaign for Tobacco-Free Kids**, which is the leading advocacy organization working to reduce tobacco use and its deadly consequences in the United States and around the world. **Our vision is a healthier and more equitable future for all**.

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Preface

At the Global Health Advocacy Incubator (GHAI), we believe in the transformative power of stories. Lived experience is an essential part of the evidence required for effective health advocacy, helping to provide a fuller picture to capture the struggles of living with chronic conditions like noncommunicable diseases (NCDs). Statistics alone cannot tell us how the daily struggles of people living with limited resources can impact health outcomes. We advocate for stronger health systems and policy change using insights from the lived realities of people living with NCDs.

NCDs are now the world's leading cause of death, responsible for over 70% of all mortality each year, with low- and middle-income countries being the most affected.[1] But epidemiological statistics, while crucial, cannot capture the barriers patients face: long walks to the nearest health center, the high cost of a month's medicines, the stigma of being a young woman with a chronic disease or the heartbreak of plunging into financial ruin.

This compendium brings together patient voices from Bangladesh, India and Nigeria, which are three countries where health systems are rapidly evolving but still leave many gaps. From village pharmacies to urban clinics, these stories reveal what it truly means to live with hypertension, diabetes and related conditions. They tell us about missed diagnoses, difficult choices between food and medicine, young people suffering from strokes and women who undermine their health to cope with their household duties.

Each story offers an invaluable insight into how health systems and policy frameworks could respond to the daily experiences that impede treatment adherence and quality of care.

We hope the stories inspire key public health decision-makers, health professionals and advocates to act with urgency, strengthen health systems and invest in prevention and treatment, ensuring that no one is left behind simply because they are poor or underprivileged.

[1] World Health Organization (WHO). (2025, September 25). *Noncommunicable diseases.* https://www.who.int/news-room/fact-sheets/detail/noncommunicable-diseases.

How Patient Voices Contribute to Policy Change

The compendium showcases one of GHAI's core strategies—patient advocacy. GHAI has historically used the insights and experiences of those living with NCDs or directly impacted by NCDs to advocate for stronger health systems and life-saving policies. We partner with and support CSOs in multiple countries, including India, Bangladesh and Nigeria, to amplify the voices of those bearing the burden of diseases that take a toll on individuals, families and communities. This is achieved through the following means:

- Cultivating and adapting context-specific strategies to identify a wide range of suitable participants and volunteers to share their stories.
- Creating a repository of participants who can be engaged for country advocacy campaigns.
- Developing and utilizing tools to consult with participants and document powerful stories and accounts of their experiences.
- Converting documented stories into various media outputs, including films, social media posters and op-eds, that can be disseminated across multiple platforms.
- Strengthening the capacity of participants to speak and share their experiences directly with government actors and policymakers.
- Providing opportunities for participants to have a seat at the table and lend their voices to policy dialogues and decision-making, such as public hearings and convenings of members of parliament.

A compelling story often speaks louder than data or numbers. GHAI is actively working with partners and advocates to shine a light on the realities of those living with chronic diseases through the use of stories and first-person narratives. Our patient advocacy approach is rooted in our call to action for government decision-makers to prioritize NCDs through increased funding and establishing patient-centered policies.

We ensure that people living with hypertension and other chronic conditions are given a seat at the table, allowing policymakers and public health officials to directly hear the realities of delayed diagnosis, medicine unaffordability, overcrowded facilities, gendered caregiving burdens, poor continuity of care and the financial consequences of illness. We have co-developed NCD-specific patient charters with patients and health care providers and presented them to policymakers. Our work has also led to governance solutions that factor in the lived experience of people. Several of the storytellers in this compendium are advocates in their own right. Naina raises awareness among women in her community about hypertension and diabetes. Shafali's message, "Don't wait for a crisis," is one GHAI continues to echo across Bangladesh. Bilkisu's and Fatima's testimonies have been presented directly to state actors in Kano State.

Importantly, this work has helped support a broader paradigm shift in how patient centricity is understood within public health systems – from hospital-acquired infections or treatment safety protocols to patient centricity in low-income and primary health care settings, focusing on quality of care, continuity of treatment, trust in public systems, medicine access and the wider social determinants of health that shape health outcomes.

Stories from **Bangladesh**



Krishno Hajong

Age: 33
Address: Thana- Durgapur, Union- Kullagora, Village- Bijoypur, District- Netrokona

How Krishno Hajong's Poorly Treated Hypertension Caused Devastation

When medicine comes from a pharmacy shelf instead of a doctor's hands, the cost can be life itself. Could better outreach have saved Krishno from lifelong dialysis?

Krishno Hajong, 33, is a daily wage earner who lives in the Durgapur Upazila (subdistrict) of Netrokona, in the Mymensingh division of Bangladesh. He lives a simple life with his aging parents, wife and 4-year-old daughter. Krishno also runs a small grocery store in his village and works tirelessly to support his family.

Two years ago, Krishno visited a local private pharmacy for a health check. Like many villagers, he relied on such pharmacies for basic health monitoring. The pharmacy assistant measured Krishno's blood pressure and found it alarmingly high at 160/90 mm Hg. By chance, Krishno discovered that he was living with hypertension.

Without consulting a registered medical doctor—the standard protocol for diagnosing hypertension—Krishno began taking medication on the advice of the pharmacy staff. He purchased his blood pressure medication directly from the pharmacy and continued using it without professional oversight. For Krishno, visiting a doctor for a proper diagnosis and treatment seemed almost impossible.

> ***"It was not easy for me,"*** he recalls. ***"The nearest doctor at the Durgapur Upazila Health Complex (UHC) was several hours away from my village. Going there would mean losing a full day's wage, plus the cost of transportation."***

Faced with these barriers, Krishno chose to self-medicate and never received confirmation of his condition or proper treatment from a qualified doctor.

For nearly two years, Krishno continued taking medication informally prescribed by the pharmacy. Over time, however, the warning signs became harder to ignore. He developed a persistent low-grade fever that lasted two weeks, swelling in his face and body that persisted for two months and noticeably reduced urination. As his condition worsened, he finally sought help from a medical doctor at the UHC, a subdistrict-level primary health care center. The diagnosis was devastating: uncontrolled hypertension had led to chronic kidney disease (CKD), a life-threatening and irreversible condition. The damage was already extensive and doctors recommended immediate dialysis.

Following the diagnosis, Krishno sought care at the Ibn Sina Diagnostic Center, a private facility in North Badda, Dhaka, registered with the Directorate General of Health Services. There, he underwent blood tests and consulted a doctor to prepare for dialysis. He then began his first dialysis session at Popular Hospital, a private facility in Dhaka. However, the high cost of treatment in private facilities quickly proved unsustainable. To reduce expenses, he moved to Shaheed Suhrawardy Medical College Hospital, a government hospital, for his next dialysis session. After returning home, he continued treatment at Sadesh Hospital, a private facility in his hometown, before finally enrolling at Bangladesh Medical University Hospital to maintain his dialysis care.

> Looking back, Krishno expresses a deep sense of regret. ***"I had no idea about the NCD services at the UHC and the services they provide, including free consultation and medicines from the government,"*** he shares. ***"Since my condition had already become complicated, I was forced to seek care from specialists in tertiary and specialty hospitals."***
>
> ***"I regret listening to the pharmacy assistant and not seeking an official diagnosis. But I also wish the health system could do more to help people like me—those who are unaware and struggling to survive daily. We would benefit from close guidance, doctors near our homes, regular follow-ups and awareness programs."***

Krishno's story is a stark reminder of the devastating consequences of undiagnosed and poorly managed hypertension. What began as a manageable condition progressed into CKD, requiring lifelong dialysis, a costly and time-consuming treatment that has left him unable to work and burdened with debt. This case highlights the urgent need for early intervention, accurate diagnosis and consistent medical supervision, which could have drastically improved his health outcomes. It also underscores the importance of raising community awareness about accessible services, such as NCD clinics at local health facilities, which provide free screening, treatment and medicines for chronic conditions.

GHAI has been collaborating with the Bangladesh government, experts, civil society organizations and media to reduce the prevalence of hypertension through timely treatment and the availability of antihypertensive medicines at the grassroots level, where they are most needed. Joint efforts have led to antihypertensive medicines being included in the existing drug list at community clinics, and the government now provides a continuous supply of free antihypertensive medicines in UHCs and community clinics. All partners are persistently working to ensure that Krishno Hajong and many others like him, who forgo a day's wage to travel to their nearest UHC to receive treatment and medicines, do not return empty-handed due to a shortage of medicines. Krishno Hajong and thousands of registered patients like him now receive calls from their nearest UHC in case they miss their monthly visits. Many registered patients' blood pressure was found to be under control during their most recent visit.

Amid the rising burden of NCDs, government health authorities must strengthen primary health care systems to ensure timely screening, early diagnosis and uninterrupted treatment. These measures are essential to preventing avoidable deaths, protecting families from catastrophic health costs and building a healthier community.



The Gender Gap in NCD Management: How Even After a Diagnosis, Shafali Found It Hard to Sustain Treatment

Between caring for her family and ignoring her own health, Shafali's untreated hypertension led to kidney failure. Why must women always come last in line for care?

Shafali is a 49-year-old homemaker and mother of four who lives in Dhupkhola, Gendaria, Dhaka. As team members from GHAI's NCD Program and colleagues of partner organizations in Bangladesh observed during a patient advocacy visit, she, like many women in her community, has dedicated her life to caring for her family and household, undermining her health in the process. Her struggles began more than 16 years ago when she was expecting her third child.

At 33, Shafali was diagnosed with hypertension during a routine prenatal check-up. *"I never imagined I had high blood pressure,"* she recalls. *"But when I went for a check-up during my pregnancy, they told me it was high."* The diagnosis was confirmed through

additional blood pressure measurements at a local pharmacy, prompting her to seek medical consultation for proper evaluation and treatment.

Following her diagnosis, Shafali began taking prescribed medication and maintained consistent follow-up care with her physician at a government hospital.

> ***"We had financial struggles at that time. Availing free treatment at the government hospital was such a boon. I took my medicines regularly because I knew it was important for me and for the baby I was carrying,"*** she explains.
>
> Over time, as Shafali got so busy taking care of her household, her adherence to her treatment and care began to decline. ***"I stopped going to the government hospital,"*** she admits. ***"Sometimes I skipped doses. I thought I was doing okay."***

Five years later, she experienced a medical emergency that required immediate hospitalization. She arrived at a private hospital's emergency department with severely elevated blood pressure readings: 250/100 mm Hg. She was admitted to the Coronary Care Unit, where doctors urgently had to administer a spray under her tongue to stabilize her condition. *"That was my first real scare," she says. "I realized then that I had ignored my condition for too long."*

Despite the warning signs, Shafali came under the full weight of taking care of her family to the extent that the years that followed were marked by inconsistent follow-ups. Over time, poorly controlled hypertension led to kidney damage, a common but often hidden consequence of long-standing high blood pressure.

Several months ago, Shafali's health declined rapidly. Medical evaluation at the Bangladesh Medical University confirmed a diagnosis of end-stage renal disease, where she was advised to begin immediate dialysis treatment.

> The treatment began with the placement of a Central Venous Catheter (CV line) to facilitate the procedure. ***"This CV line is very painful,"*** Shafali explains, her voice breaking. ***"It's hard to bear, both physically and mentally."*** Each dialysis session costs the family 3,000 taka (US$24.55), an emotional and financial burden they now carry multiple times a week.
>
> Sitting beside her husband, who tirelessly supports her through every appointment, Shafali reflects with regret: ***"If I had been more cautious about my hypertension... if I had taken my medicines regularly, maybe this day wouldn't have come."***

Her story reminds us that chronic conditions like hypertension are simple to treat. But if left neglected, the consequences can be severe and life-altering.

Shafali's message to others is simple yet powerful: *"Don't wait for a crisis. Take care of your health before it's too late."* This is a message GHAI will continue to echo as it works alongside Bangladeshi partners such as the National Heart Foundation of Bangladesh, PROGGA (meaning "Knowledge for Progress"), Bangladesh Medical University and the government to ensure life-saving hypertension medicines and care reach the people who need them most, especially in rural areas. Through sustained advocacy for greater budget allocation, medicine supply chains and accessible primary health care, GHAI works to ensure that people like Krishno and Shafali can access proper diagnosis close to home and receive the support needed to maintain life-saving treatment. Sustained support for this advocacy means more people like Krishno and Shafali are diagnosed early and stay on treatment.

Stories from **India**



Sarita

Age: 50
Address: Rishikesh, Uttarakhand, India

Tired of Hospital Queues and Outpatient Waiting Time, Sarita Gave Up Treatment

Long lines and lost wages turned Sarita away from free medicine—and toward a stroke that changed her life. What good is access if it is out of reach?

Sarita, 50, lives in a densely populated urban slum in Rishikesh, a holy city tucked away in the Himalayas. Although Rishikesh is a rapidly growing urban center and a global tourist spot, public health infrastructure is overburdened with patients from remote mountain areas and nearby towns.

Sarita and her husband ran a modest food stall, where they worked long hours to make ends meet. For over two years, Sarita frequently experienced dizziness and persistent headaches. However, like many women balancing household responsibilities and financial pressures, Sarita pushed aside her own discomfort. There was never enough time or money to visit a doctor. Health facilities close to her house had irregular outpatient department timing, and they never matched her busy schedule.

Then, six months ago, everything changed.

One day, Sarita felt sudden numbness on one side of her body. She could not move her arm or leg. Her husband immediately rushed her to a city hospital, where she was diagnosed with a stroke that was triggered by uncontrolled hypertension and diabetes – both undetected and untreated for years.

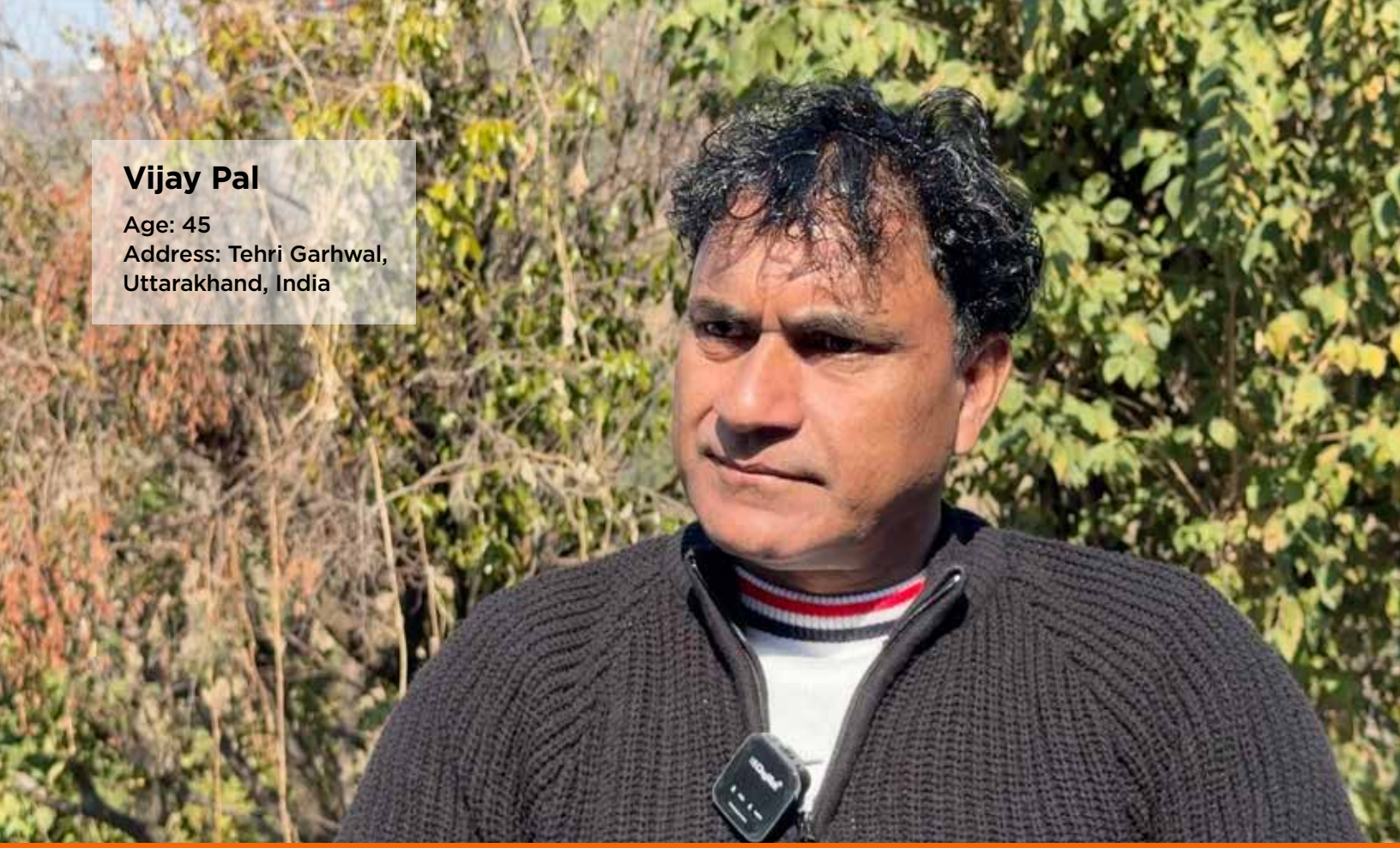
Today, Sarita lives with a partial disability. She can no longer work at the food stall. Even small chores seem mountainous. Her husband now shoulders the burden of caring for her, cooking, managing household duties and running the food stall. To manage her condition, Sarita takes several daily medications, ranging from pills to control her blood pressure and diabetes to statins and blood thinners — all of which she must take for the rest of her life. While these medicines are part of the government's essential medicine list and can be obtained free of charge from public dispensaries, the waiting time at these facilities is daunting.

She has no choice but to seek care at a local private clinic, spending ₹4,000–₹5,000 (about US$46-US$57) per month on medicines and check-ups, which is a devastating cost for a low-income family.

Once an active person and the main caregiver in the family, Sarita can only watch from the sidelines with growing frustration and sadness, as her husband struggles to cope.

> ***"If I had known how dangerous those seemingly minor symptoms were, I would have taken prompt action. But the idea of seeing a doctor and then spending a whole day to get medicines from the government pharmacy is so discouraging that we end up not seeking treatment. I wish there was a way for health care and medicines to be made available easily to people like us who live hand to mouth,"*** she explains.

Through stories like Sarita's, our partner institution, AIIMS Rishikesh, identified that long outpatient queues, inconvenient pharmacy hours, overcrowded facilities and loss of daily wages were major reasons why patients discontinued treatment even when medicines were technically "free." In response, efforts were initiated to improve patient navigation and access within hospital systems, including streamlining patient flow and strengthening support for chronic disease follow-up. AIIMS Rishikesh also conducted Continuing Medical Education (CME) sessions with doctors and health care providers focused on patient centricity—encouraging clinicians to better understand the lived realities, economic pressures and social barriers faced by patients with chronic illnesses like hypertension. Insights from patient voices like hers are informing broader system-level efforts to strengthen continuity of care through Comprehensive Primary Health Care and to build more patient-friendly services.



Vijay Pal

Age: 45
Address: Tehri Garhwal, Uttarakhand, India

When Vijay Suffered a Stroke in a Remote Himalayan Village, the Road to Care Was Long and Arduous

With no road, no ambulance and fading breath, his family carried him through the mountains. Would he reach care in time?

Vijay Pal, 45, lives in a remote Himalayan village in Uttarakhand's Tehri district. To reach the nearest health facility, people from his village walk long distances on rugged mountain paths to the bus stop, where buses only run twice daily. The services stop entirely during inclement weather, when roads wash away. Absence of nearby health facilities makes it impossible to get timely treatment for emergencies such as a stroke, which must be treated within the golden period.

Six years ago, Vijay was diagnosed with high blood pressure, but like many people in low-resource settings, he underestimated its danger. He was given medication but rarely took it consistently. He would stop taking his blood pressure pills as soon as the symptoms went away. Vijay turned to home remedies and practiced yoga, convinced that

lifestyle changes alone would be enough. His reluctance to take medicines stems from fear of side effects and local misconceptions about medications (e.g., medications associated with addiction, risks of damaged eyesight, adverse effects on cardiovascular health and premature aging).

One of Vijay's neighbors had a blood pressure machine, which Vijay often used to monitor his blood pressure. Despite persistently high readings, he did not seek treatment. Last year, he suffered a stroke that resulted in partial paralysis on the left side of his body. In a village without road access or ambulance services, getting emergency care became a crisis in itself. His family had to carry him on foot through steep trails to the nearest point where a vehicle could reach. From there, they traveled nearly 150 kilometers to reach a private hospital in the city.

Vijay has now returned home, slowly working toward recovery. He often feels weak, suffers from dizziness, has to walk with support.

Despite taking regular medications, his blood pressure is unstable. Public health care options near his village are scarce as Tehri district, like many parts of the Himalayan region, struggles with limited functional Primary Health Centers and a shortage of doctors in remote blocks. As a result, patients like Vijay have no option but to rely on expensive private care far from home, even for routine follow-ups.

> ***"It was very hard for me when the stroke happened. My relatives and neighbors had to carry me on their shoulders through narrow village paths just to get me to a vehicle,"*** he says.

Vijay's story reveals the multiple barriers that rural and low-income patients face: limited awareness about chronic conditions like hypertension, fear and misinformation about medication and inadequate medical infrastructure. Most critically, his story highlights the gaps in emergency and ongoing care in remote areas.

Vijay's story is a powerful "near-miss" learning case for the health system. His delayed treatment underlined the need to expand primary care closer to remote villages, strengthen blood pressure screening before complications occur and ensure that patients remain on medicines after an acute event. In India, an estimated 220 million people live with hypertension and only about 12% have it under control, making uncontrolled blood pressure one of the country's leading risk factors for death and disability. This aligns with India's Ayushman Bharat approach to expand the reach of community health clinics to serve the remotest areas of India. Lessons from these stories also strengthen the evidence to advocate for screening for hypertension and other common NCDs among younger people, including those above 18. Our partner AIIMS Rishikesh, recognizing the need for last-mile innovation, piloted drone delivery of medicines to Tehri, the remote area of the Himalayas that Vijay hails from. One documented drone delivery covered 36 km by air in 29 minutes, compared with a much longer 72 km road journey taking 2.5–3 hours. These roads are often impacted by inclement weather and landslides, cutting off medicine supply for months every year. Such tech-driven local governance solutions can reshape NCD control.



Paras Mal

Age: 70
Address: Jodhpur, India

How Lack of Trust in Public Health Facilities Delayed Paras Mal's Diagnosis and Treatment

For years, Paras dismissed his blood pressure as a minor annoyance. It took a heart attack—and two stents—for him to finally believe the quiet dangers of neglect.

Paras Mal is a resident of Jodhpur, a desert town in the state of Rajasthan, India. Paras, once a shop owner, now leads a quiet, retired life. A self-reliant person, Paras manages his household and occasionally serves customers from his old trade.

Like many older adults in India, Paras lived for years with undiagnosed hypertension. He had never felt ill enough to visit a doctor, and like others in his community, he wasn't aware of the dangers posed by untreated high blood pressure. The idea of going to a government hospital didn't cross his mind. *"I didn't even know Primary Health Centers gave free blood pressure medicines,"* he recalls.

On a late November morning in 2004, Paras felt unusually breathless. A heaviness gripped his chest. By the time he reached a nearby hospital, it was clear something serious was happening.

Doctors told him that he had suffered a heart attack. Paras was rushed in for an emergency procedure, and two stents were inserted to treat blockages in his arteries. It was only then, in a hospital bed, recovering from the shock, that he heard the word "hypertension" used in relation to his condition.

> ***"I used to think high blood pressure was just a small issue—something that comes and goes. It wasn't until I had a heart attack that I realized it had been silently hurting me for years."***

After the surgery, Paras knew things had to change. His recovery was supported by follow-ups at the local Primary Health Center and regular counseling. Doctors explained the importance of never missing a dose and that he would have to be on lifelong medication. Free medicines, combined with dietary guidance and emotional reassurance, helped Paras remain on treatment. As a result of regular visits to the health facility, doctors were able to detect that he was suffering from anemia and he was put on an iron-rich diet.

The long waiting time at the outpatient department and a lack of trust in practitioners at public health facilities had prompted Paras to seek treatment at an expensive private hospital. However, the quality of care, follow-up support and regular medicine supply at the local Primary Health Center (PHC), supervised by the super specialty tertiary care hospital, All India Institute of Medical Sciences (AIIMS), turned him around and he began relying on them and the PHC fully for his follow-up treatment. Paras described the PHC staff as instrumental in his recovery and health.

> ***"They explain things, they remind me to take my medicine, and now I never skip a dose. I also tell my friends—don't wait till something big happens. Get checked. Trust the system."***

Paras Mal's story is a reminder that if detected late, hypertension could lead to a heart attack or stroke. Often, the delay isn't due to lack of access but lack of awareness and distrust of public health systems that discourage patients from using health services even if they are close to home and free. Quality of care and patient counseling are simple tools that can reverse loss to follow-up and poor treatment adherence.

Through qualitative evidence emerging from stories like his, AIIMS Jodhpur was able to demonstrate to the Rajasthan NCD Task Force that patient adherence improves significantly when public systems invest in quality of care, counseling, follow-up and continuity of treatment, not just diagnosis. These learnings informed a broader series of trainings and sensitization programs for public health officials and health care providers on patient centricity in NCD care. As a result, a stronger patient-centered approach has begun to emerge across both tertiary hospitals and primary health care facilities. Greater emphasis is now being placed on counseling patients after acute cardiac events, improving communication between providers and patients, reducing loss to follow-up and strengthening the practice of dispensing medicines for at least one month at a time for patients on chronic NCD treatment.



Naina Prakash

Age: 42
Address: Jodhpur, Rajasthan, India

How Naina Prioritized Her Health Despite Household Duties

Between cooking, cleaning and caring for ten others, Naina forgot herself. Then exhaustion forced a reckoning. For once, she chose her own life—and it made all the difference

Naina Prakash shares a home with 10 people in Pratap Nagar, a locality in Jodhpur, India. At 42, Naina has spent most of her adult life as the family caretaker—managing the household, raising four children and helping with their small business. Between the three people in her family who work, they make about ₹50,000 (about US$570) per month.

Naina married young after primary school and quickly learned to put everyone else's needs first. When she started feeling constantly exhausted, she just assumed it was normal.

Two years ago, Naina began feeling persistently weak, drowsy and fatigued. At first, Naina ignored the symptoms, brushing them aside as signs of overwork. When the fatigue became unbearable, she visited the Pratap Nagar Satellite Clinic and received unexpected results. She had high blood glucose levels, which confirmed she had diabetes.

During a routine follow-up appointment two months later, she was diagnosed with another underlying health condition: hypertension. Naina's recent diagnosis with both hypertension and diabetes came as a shock but also served as a wake-up call for Naina to prioritize her health.

Naina took her diagnoses seriously, and with the guidance of health care providers at the clinic, she began taking medication regularly. She restricted her diet, avoiding excess salt and sugar, and began walking daily. Over time, she started noticing improvements in her health, including higher energy levels and controlled blood pressure and blood sugar readings.

Naina is grateful for the care and support she receives from the local health facility.

> ***"Whenever I visit the clinic, the doctors and health workers explain everything to me patiently,"*** she shares. She appreciates the availability of free medicines and regular check-ups, which have helped her manage her health without increasing financial strain on her family. The health care staff's encouragement and her family's support have made it easier for Naina to stay consistent with her treatment.

Naina is committed to raising awareness among women in her community about the serious risks posed by hypertension and diabetes.

> ***"Health is not something you can ignore,"*** she says. ***"I want to live well—not just for myself, but for my children."***

Naina's journey is a powerful reminder that when women have access to reliable health information and quality care, they are empowered to make informed decisions that transform not only their own lives but also the well-being of their families and communities.

Like Naina, many young women in India are increasingly experiencing the comorbidity of diabetes and hypertension. These conditions often emerge silently, and screening or diagnosis is frequently delayed because women shoulder a disproportionate share of household and caregiving responsibilities. Naina's experience shows how early detection, free essential medicines and supportive providers within easy reach can fundamentally change the course of chronic disease management. Yet many women across the country still lack consistent access to these services.

To address these gaps, we work closely with our partners AIIMS Jodhpur, state governments and the National NCD Program of the Ministry of Health and Family Welfare to strengthen the governance and delivery of hypertension and diabetes care at the primary health care level. We provide technical support and draw insights from our work in communities to make services more effective and equitable. By elevating lived experience as evidence, GHAI aims to ensure that women like Naina receive the timely, accessible and affordable care they need to live healthier, fuller lives. With sustained support, GHAI and its partners can extend these gains to millions more women across India.

Stories from
Nigeria



Bilkisu

Age: 50
Address: Kano State, Nigeria

How Patriarchy and Lack of Autonomy in Health Care Decisions Trapped Bilkisu in a Cycle of Suffering

When her husband controlled the purse, Bilkisu had medicine. When he died, she had none. When health care decisions depend only on men, what happens when they are gone?

Bilkisu Abdullahi Usman, a 50-year-old widow in Kano State, Nigeria, lives in a rural farming community with a dry climate, seasonal droughts and limited health infrastructure. As GHAI staff sat with her in one of our sessions to document patient stories on hypertension and health systems, her story began to unfold. Supporting herself and her children through subsistence farming, she earns less than N10,000 monthly (US$7).

After marriage, Bilkisu found herself isolated like many women in her community, separated from her own family and expected to adapt to her husband's household with little say and limited support. She was 35 when she began experiencing sharp shoulder pain.
At the time, she *"thought it was from hard work or harmattan cold,"* she recalls, referring to the dry, dusty wind that blows from the Sahara across West Africa between November and March, often bringing a sharp chill in the mornings and nights. Hot water compresses provided no relief, so she visited a nearby public hospital, where she was diagnosed with high blood pressure or hypertension.

> ***"I didn't know something like high blood pressure could give you pain,"*** she says.
> Her husband took responsibility for her care, purchasing medications and attending check-ups. Her husband often bought medications from any available pharmacy and in some cases, followed the pharmacist's advice instead of the doctor's prescription. This arrangement sometimes resulted in proxy treatment, which led to irregular blood pressure monitoring and treatment decisions made without her full understanding or awareness. For many women in Bilkisu's community, men oversee their health care decisions.

But everything changed when her husband died.

Now responsible for purchasing her own medication, Bilkisu faced an impossible financial burden. Drugs like Amlodipine and Lisinopril cost N3,000-5,000 (about US$2 to US$3.50) monthly in public pharmacies (or more in private facilities), which is up to half of her farming income. During medical emergencies when her blood pressure spikes, she can get dizzy, faint or experience chest tightness. At such instances, costs can exceed N30,000 (about US$20). For someone without savings or health insurance, these expenses can be devastating.

The consequences for her family were immediate. Her 15-year-old son dropped out of school to support her by working odd jobs. *"He wanted to go back to school, but I told him to wait until I got better,"* she says. Without her medication, Bilkisu's health worsens, making it harder for her to farm and earn the money she needs for treatment. This creates an impossible choice between buying medicine and feeding her family.

> ***"If I could just go to the Primary Health Center and get my blood pressure medicine for free, my son would be back in school and I wouldn't be missing my doses,"*** Bilkisu pleads. ***"I just want to stay alive to care for my children."***

The intersection of poverty, gender norms and a weak health system has left women like Bilkisu caught in ongoing cycles of suffering and hardship.

Bilkisu's story became a powerful advocacy tool for our partner, GAMMUN Center for Care and Development Nigeria (GCCDN). It amplifies the real-life consequences of weak primary health care systems, poor domestic funding and limited access to affordable medicines. Through advocacy engagement meetings, it encouraged state actors to increase disbursement of approved NCD funds by 25% in 2025 and opened discussions on more sustainable access to affordable antihypertensive medicines. Ultimately, Bilkisu's story became more than a patient testimony; it evolved into evidence for advocacy, helping to drive momentum for stronger, more inclusive and resilient health systems reforms in Kano State.



Fatima

Age: 26
Address: Kano State, Nigeria

How Young Fatima's Pre-Eclampsia Destroyed Her Marriage, Her Health and Her Future

At 26, Fatima should have been chasing dreams. Instead, she chases breath between dialysis sessions. Must poverty still be a death sentence for many young women?

Fatima Abubakar Kabo, 26, is a university graduate and mother of two in Kano State, Nigeria, where access to health care for chronic diseases is limited and gender inequality prevents many women from seeking care independently.

Two years ago, she was diagnosed with high blood pressure during a routine pregnancy check-up. After her second child's birth, her condition worsened and now she lives with second-stage hypertension, a severe form of high blood pressure that significantly increases the risk of heart attack, stroke and organ damage. She also has early-stage heart failure and kidney dysfunction.

Her symptoms—chronic fatigue, chest pain, dizziness and shortness of breath—became so debilitating that she struggled to take care of her newborn. The baby was prematurely weaned, and family members had to step in.

"My baby doesn't even know me," she says. "*She was raised by my cousin while I was too weak to carry her."*

Unable to fulfill her expected roles as a wife and mother due to her condition, Fatima was abandoned by her husband. Unwilling to bear the rising cost of her treatment and the social stigma of having a sick wife, he left and remarried.

> Today, Fatima lives with her elderly mother, who also has hypertension, and cares for her surviving child completely alone. ***"It's a challenging one, managing my illness and taking care of my kid,"*** Fatima explains. ***"I lost the first child, but the second baby is with me. I take care of her needs all alone, with no support from her father nor his family."***

Fatima undergoes dialysis three times a week, a life-saving treatment that consumes nearly all her savings. Her monthly medical expenses are around N95,000 (about US$62), including medications like diuretics, beta-blockers, renal support therapy and diagnostic tests. Without regular income or insurance, Fatima sometimes has no choice but to skip medication, which often leads to health emergencies requiring ambulance transport and hospitalization.

Despite her education, Fatima's aspirations have narrowed down to one simple goal: survival, for herself and her children. *"I used to want to start a business and be independent. Now my only goal is to find money for my medicines,"* she says.

Fatima's story highlights the particular vulnerability of women with chronic conditions. Regressive social norms and gender-based discrimination can strip women of support, access to care and dignity, leading to avoidable tragedies and lost lives.

Time-sensitive measures such as free, regular access to essential medicines at primary health centers, financial protection and insurance coverage for vulnerable women with chronic conditions and community support programs to reduce stigma and ensure continuity of care could help save young women like Fatima.

> ***"Let there be free medicine,"*** Fatima pleads. ***"Let us not die because we are poor women."***

Fatima's story demonstrates that strategic improvements to Nigeria's health system could prevent similar hardships. GHAI has partnered with the GAMMUN Center for Care and Development Nigeria to provide strategic and technical engagement with key government and non-government stakeholders, including the media and civil society partners, to support evidence-based policies through the revived Kano State NCD steering committee and newly introduced quarterly engagement meetings between state actors and the hypertension patient association, increase resource allocation and strengthen the effective use of appropriated funds for NCDs. Ensuring the availability of affordable medications at primary health care centers, expanding health insurance coverage and providing targeted support for patients will directly address the challenges faced by Bilkisu, Fatima and others. Investing in this advocacy means fewer families face such impossible choices.

ABOUT THE GLOBAL HEALTH ADVOCACY INCUBATOR:

The **Global Health Advocacy Incubator** uses the power of advocacy to tackle critical public health challenges across the globe – including food and nutrition policy, injury and overdose prevention, and building resilient and equitable health systems.

We are an initiative of the **Campaign for Tobacco-Free Kids**, which is the leading advocacy organization working to reduce tobacco use and its deadly consequences in the United States and around the world.

Our vision is a healthier and more equitable future for all.

For more information about GHAI, visit www.advocacyincubator.org

An Ask: Help Us Change the Story

Behind every voice in this compendium stand millions more people who remain undiagnosed, untreated and unheard. Funders can change that. We invite you to support GHAI's budget and policy advocacy work on hypertension and other NCDs in Bangladesh, India and Nigeria. Your investment keeps essential medicines free and available, brings care closer to home and helps more people like Krishno, Naina and Bilkisu live full lives.

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