

NCAER NATIONAL DATA INNOVATION CENTER
MEASUREMENT BRIEF 2024
NDIC FELLOWS PROGRAMME

Hidden Diabetes in India



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Overview and Measurement Challenge

In India, an estimated 77 million people above the age of 18 suffer from only Type 2 diabetes, but approximately 50% are unaware that they have diabetes. This brief attempts to estimate the prevalence and burden of 'hidden diabetes' in India and its states. Diabetes is a condition characterized by blood glucose levels that exceed medically recommended limits, including type 1, type 2, gestational diabetes, etc. Hidden diabetes refers to a situation where a person has elevated blood glucose levels but is unaware of their condition and has not been informed about it by healthcare professionals.

Real-time diabetes data surveillance is critical for formulating and monitoring effective diabetes prevention policies and programmes. However, the lack of real-time data on diabetes has compelled studies to rely on large-scale survey data like the National Family Health Survey (NFHS) to estimate the prevalence of diabetes at both the macro and micro levels in India. Using this survey data, studies have highlighted significant discrepancies between self-reported diabetes and diabetes measured through biomarkers, indicating potential underestimation or overestimation issues (Maiti et al. 2023; Puri et al., 2020). One study has estimated the prevalence of awareness, treatment, and control of diabetes (Maiti et al. 2023); however, the prevalence and burden of hidden diabetes have not been estimated. Therefore, this study attempts to estimate the prevalence and burden of hidden diabetes in India.

Diabetes is measured using large-scale survey data in three ways: self-reported, diagnosed, and measured diabetes. *Self-reported diabetes* refers to cases where individuals indicate that they are currently having diabetes. *Diagnosed diabetes* occurs when individuals report that a healthcare professional has informed them on two or more occasions that they have the condition. *Measured diabetes* is determined when an individual's blood glucose level is 140 mg/dL or higher, based on a blood test. Hidden diabetes is defined as the diabetic condition of individuals who reported 'no' or 'don't know' on *self-reported diabetes* and 'no' on *diagnosed diabetes*, but their blood glucose level is more than 140 mg/dl identified from a blood test. On the other hand,

awareness of diabetes is defined if individuals report that they have been diagnosed with diabetes (Maiti et al. 2023). For the estimation of hidden diabetes, the age and sex structure of the population and population size projected by the Ministry of Health and Family Welfare (2019) across the states were taken into consideration.

KEY RESULTS



- **Every one in ten individuals in India has hidden diabetes.** About 8.8% of India's population has hidden diabetes.
- **India has 119 million hidden diabetic cases.** About 53.3 million cases are females and 65.6 million cases are males. About 73.7 million and 45.2 million hidden diabetic cases are living in rural and urban areas respectively.
- **Males have higher hidden diabetes than females.** The prevalence of hidden diabetes is higher among males at 11% than females at 8.5%.
- **Urban areas have a higher prevalence of hidden diabetes than their rural counterpart.** The prevalence of hidden diabetes in urban and rural areas is 9.8% and 8.4% respectively.
- **Large populous states of India share the largest burden of hidden diabetic cases.** Uttar Pradesh had the highest share at 15% (18 million), followed by West Bengal at 10% (12 million), Bihar at 10% (12 million), Maharashtra at 9% (11 million), Tamil Nadu at 7% (8 million), Gujarat at 7% (8 million), and Madhya Pradesh at 6% (7 million).
- **Medium and small populous states have the highest prevalence of hidden diabetic cases.** It was highest in Tripura (13.6%) followed by Dadra & Nagar Haveli and Daman & Diu (12.5%), Goa (12.1%), West Bengal (12%), Andaman & Nicobar Islands (11.5%) and Gujarat (11.3%).

for 2020 was taken from the National Commission on Population, Ministry of Health & Family Welfare, Government of India (2019).

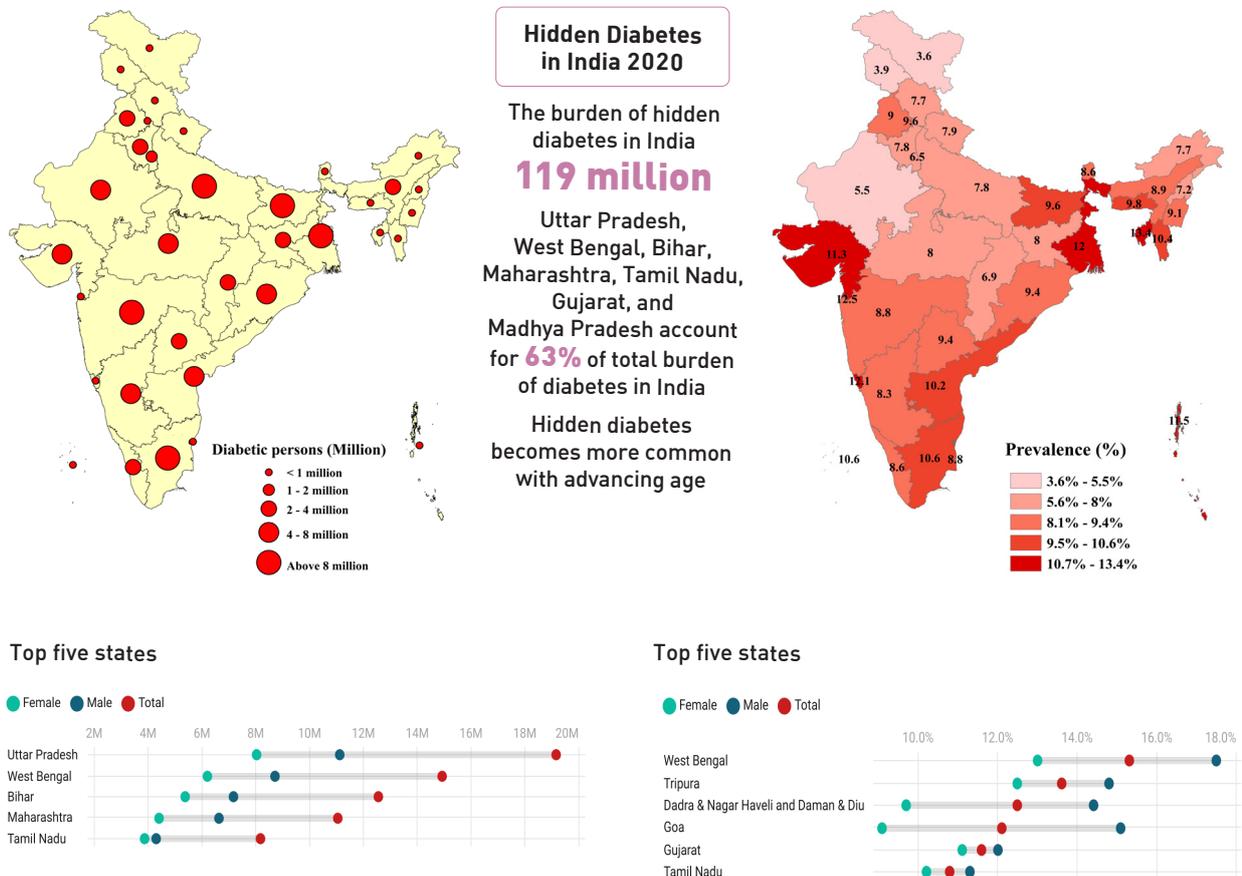
Measuring Hidden Diabetes

Women respondents aged 15–49 years and men aged 15–54 years were asked if they currently had diabetes. Positive responses were categorized as *self-reported diabetes*. In the biomarker questionnaire, individuals aged 15+ years were asked if they had been diagnosed with high blood glucose on two or more occasions as conveyed by the health professionals. Those answering ‘yes’ were categorized as having been *diagnosed with diabetes or diagnosed diabetes*. On the contrary, *undiagnosed diabetes* is defined as individuals who were not diagnosed on two or more occasions. All individuals aged 15+ years also underwent a finger-stick blood glucose test during the survey. Elevated blood glucose was defined as levels between 141–160 mg/dl, and significantly high levels as above 160 mg/dl. Hidden diabetes is defined as individuals who reported ‘no’ or ‘don’t know’ for *self-reported* as well as *diagnosed diabetes* but had blood glucose levels above 140 mg/dl.

The following steps were followed to estimate the burden (number) and prevalence of hidden diabetes in India and its states.

1. The percentage of hidden diabetes for women (15–49 years) and men (15–54 years) by five-year age groups separately for rural and urban areas from NFHS (2019–21) data, applying appropriate weights.
2. The percentage of hidden diabetes for women aged 50+ years and men aged 55+ years is estimated separately by multiplying the respective ratio of undiagnosed diabetes between consecutive five-year age groups with hidden diabetes. For example, the prevalence of undiagnosed diabetes among women aged 45–49 years and 50–54 years are 13.5% and 16.6% in India, respectively. Thus, the ratio of undiagnosed diabetes between two consecutive five-year age groups for the age group 50–54 years is 1.2 (16.6/13.5). The prevalence of hidden diabetes for the age group 45–49 years is 12.2%. The estimated prevalence of

Figure 1: Graphical abstract



hidden diabetes for the age group 50-54 years is 15.1% (12.2*1.2).

3. The number of hidden diabetic cases in each five-year age group for 2020 is estimated by multiplying the percentage (proportion) of hidden diabetes by the population size of the respective five-year age group. The population for 2020 in each five-year age group is estimated from the total projected population for the year by multiplying the proportion share of each five-year age group by to total population of 2011 (Census of India 2011). The total number of hidden diabetes is computed by summing the cases of all age groups separately for females and males in rural and urban areas.
4. The prevalence of hidden diabetes is calculated by dividing the number of hidden diabetes cases by the total projected population for 2020 and multiplying by 100 separately for females and males in rural and urban areas.

It is important to note that separate analyses for rural and urban areas were not conducted for small states and union territories due to either the unavailability of segregated rural-urban population data or insufficient sample sizes in these areas for estimating hidden diabetes by age and sex. The states where separate analyses were conducted are listed in Supplementary Table 3.

Results

Every one in ten individuals in India has hidden diabetes. About 8.8% of India's population has hidden diabetes (Suppl. Table 2).

India has 119 million hidden diabetic cases. About 53.3 million cases are female and 65.6 million cases are male (Suppl. Table 2).

Males have higher hidden diabetes than females. The prevalence of hidden diabetes is higher among males at 9.5% than females at 8.1% in India. The prevalence of hidden diabetes is higher among females in all states of India except for Jammu & Kashmir, Himachal Pradesh, Kerala, Chandigarh, and West Bengal (Figure 2 on Page 4).

Urban areas have a higher prevalence of hidden diabetes than their rural counterpart. The prevalence of hidden diabetes in urban and rural areas is 9.8% and 8.4% respectively. A higher prevalence of diabetic cases is found in all large states and union territories except for Odisha, Karnataka, Uttar Pradesh, Uttarakhand, Himachal Pradesh, and Rajasthan (Figure 3 on Page 6).

Hidden diabetes increases with age in both sexes. The prevalence of hidden gradually increases with advancing age. For example, the prevalence is 2.5% in 15-19 years which is 12.3% in the age group of 45-49 years among women. Further, it is projected to be 19.1% among women in the age group 80+ years in India. Similarly, among men, the percentage of hidden diabetes is 3.0% in the age group of 15-19 years and it is 17.9% in the age group of 50-54 years which is projected to be 21.2% in 80+ years (Suppl. Figure 1).

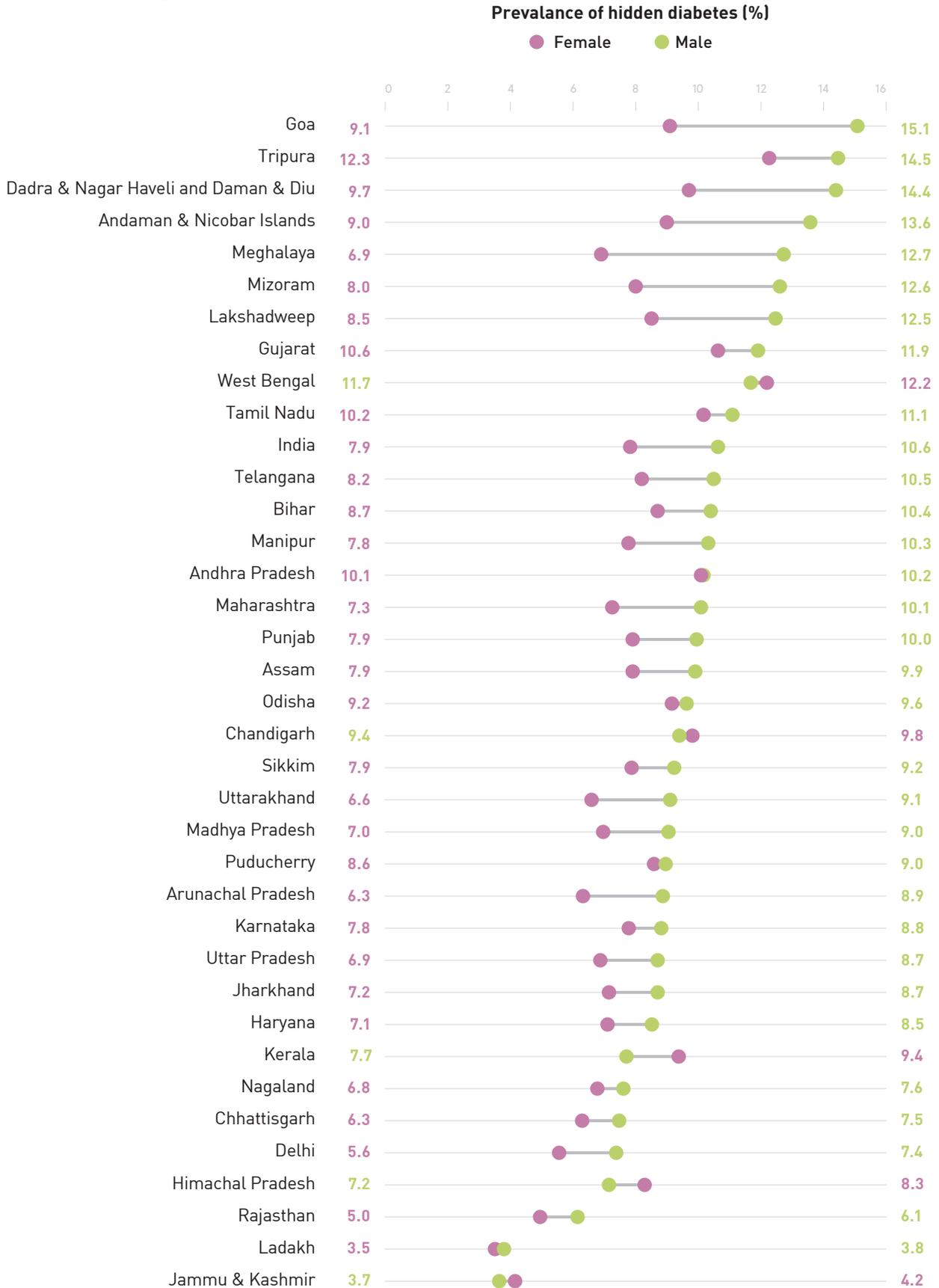
Large populous states of India share the largest burden of hidden diabetic cases. Uttar Pradesh had the highest share at 15% (18 million), followed by West Bengal at 10% (12 million), Bihar at 10% (12 million), Maharashtra at 9% (11 million), Tamil Nadu at 7% (8 million), Gujarat at 7% (8 million), and Madhya Pradesh at 6% (7 million) (Figure 4a on Page 7).

Medium and small populous states have the highest prevalence of hidden diabetic cases. It was highest in Tripura (13.6%) followed by Dadra & Nagar Haveli and Daman & Diu (12.5%), Goa (12.1%), West Bengal (12%), Andaman & Nicobar Islands (11.5%) and Gujarat (11.3%). Additionally, it was slightly higher in Lakshadweep, Tamil Nadu, Mizoram, Andhra Pradesh, Meghalaya, Chandigarh, Bihar, Odisha, Telangana, and Manipur (ranging from 9% to 10.6%) than the national average (8.8%) (Figure 4b on Page 7).

Policy Lessons

The Ministry of Health & Family Welfare, Government of India strategized population-based screening of common non-communicable diseases including diabetes under the programme of "National Programme for Prevention & Control of Cancer, Diabetes, Cardiovascular Diseases & stroke (NPCDCS)". However, the current situation of hidden diabetes among people remains a grave concern because one in every ten Indi-

Figure 2: Prevalence of Hidden Diabetes Among Females and Males Across the States of India, 2020



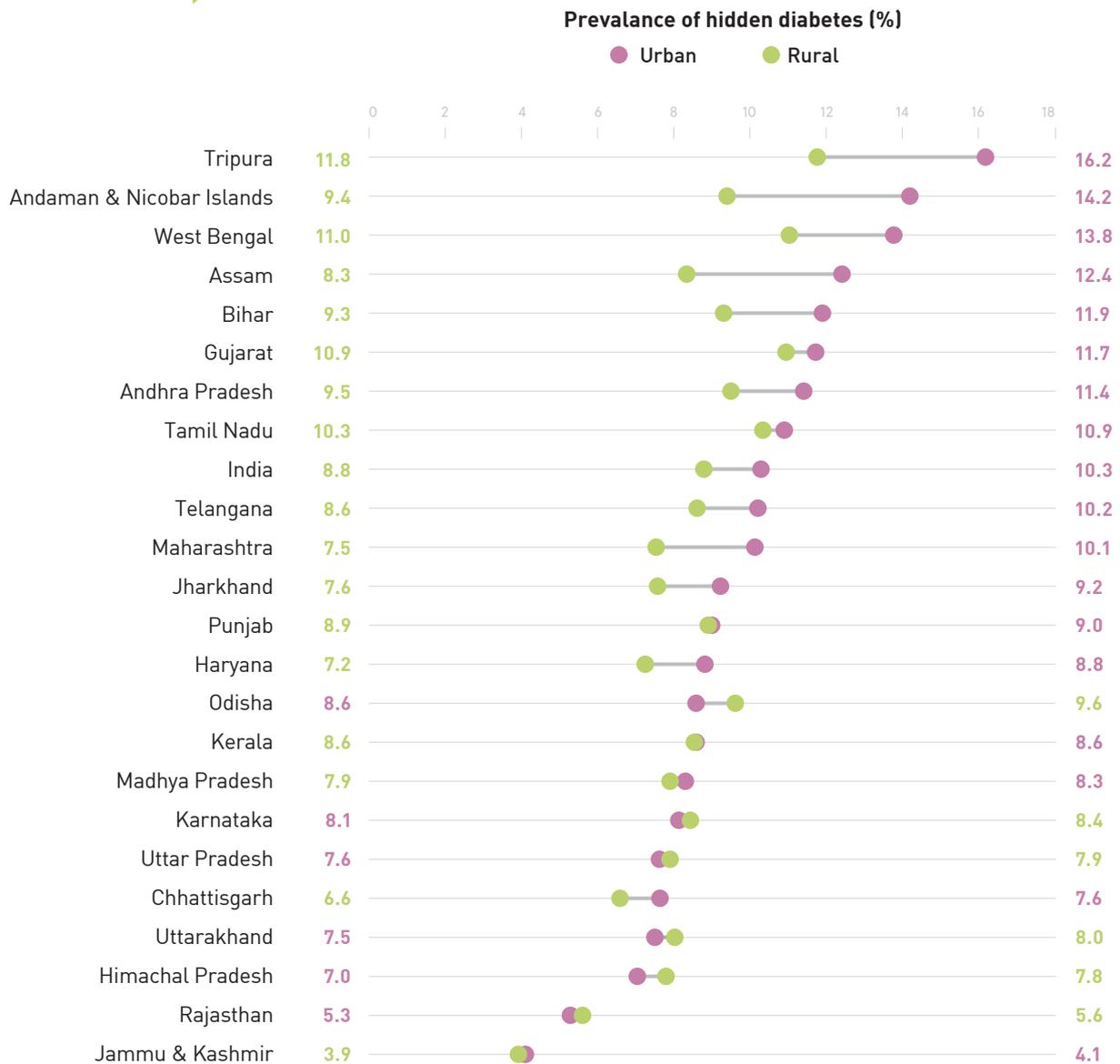
ans has hidden diabetes. The following policy lessons may be recommended for uncovering hidden diabetes in India.

- Strengthening healthcare infrastructure and training frontline healthcare professionals like ASHA and Anganwadi workers can be a positive step towards the early detection of hidden diabetes particularly in underserved areas.
- Implementation of nationwide awareness campaigns to educate people about diabetes, its risk factors, symptoms, and the importance of regular

screening. The campaigns should reach diverse populations with a special focus on the aged and male population in urban areas.

- The population at risk of hidden diabetes should be targeted for screening with a priority on the most vulnerable states of India.
- A robust system of databases on the risk factors of diabetes may help identify the cases of hidden diabetes. This includes creating a national registry for diabetes and its risk factors to track cases and trends over time.

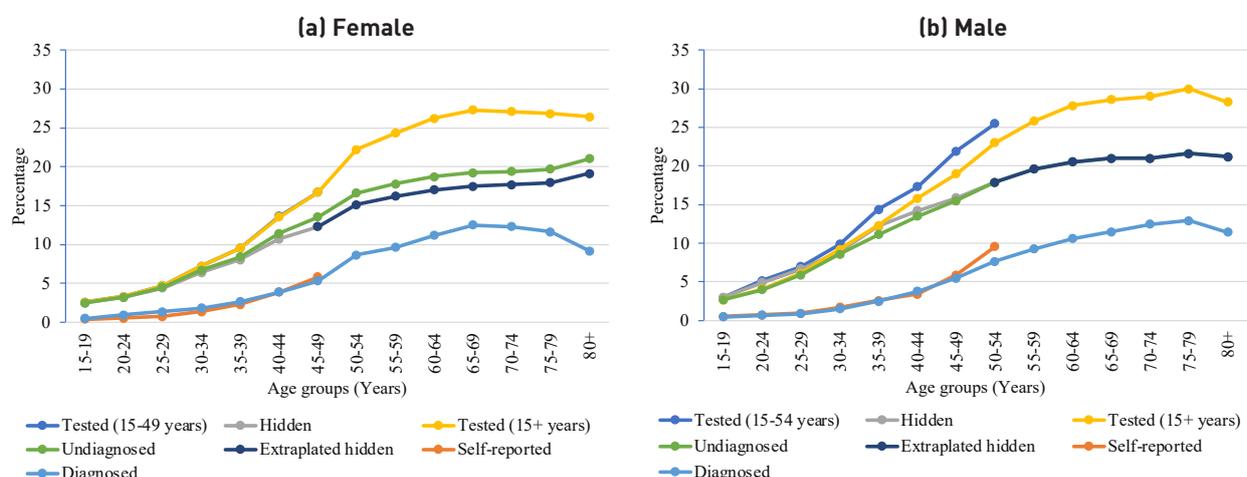
Figure 3: Prevalence of Hidden Diabetes in Rural and Urban Areas Across the States of India, 2020



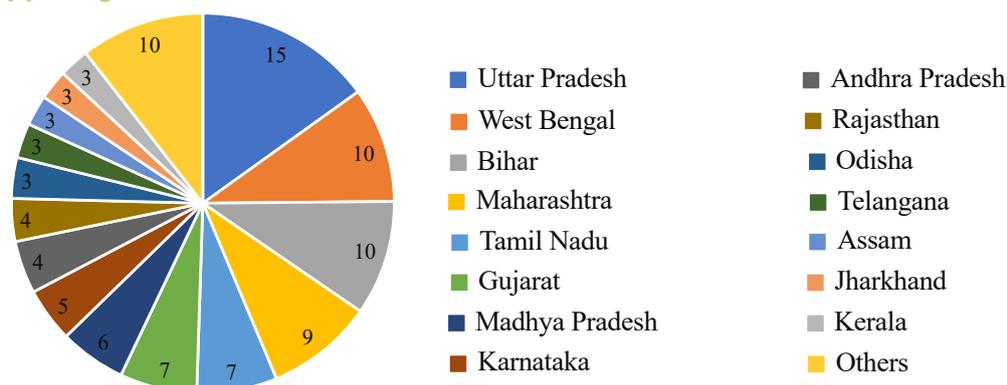
Suppl. Table 1: Sensitivity and specificity analyses (a) between self-reported and diagnosed diabetes, (b) between self-reported and tested diabetes, and (c) between hidden and tested diabetes

Diabetes measures	Women (15-49 years)	Men (15-54 years)
(a) self-reported and diagnosed diabetes		
Sensitivity	35.8 (35.7, 35.9)	35.8 (35.7, 35.9)
Specificity	98.7 (98.7, 98.7)	98.7 (98.7, 98.7)
Positive predictive value	32 (31.9, 32.1)	32 (31.9, 32.1)
Negative predictive value	98.9 (98.9, 98.9)	98.9 (98.9, 98.9)
Prevalence	1.7 (1.7, 1.7)	1.7 (1.7, 1.7)
Observations	6,89,970	6,89,970
(b) Self-reported and tested diabetes		
Sensitivity	42.3 (42.2, 42.5)	42.3 (42.2, 42.5)
Specificity	93.9 (93.8, 94)	93.9 (93.8, 94)
Positive predictive value	10.6 (10.5, 10.7)	10.6 (10.5, 10.7)
Negative predictive value	99 (98.9, 99)	99 (98.9, 99)
Prevalence	1.7 (1.7, 1.7)	1.7 (1.7, 1.7)
Observations	6,90,748	6,90,748
(c) Hidden and tested diabetes		
Sensitivity	33.4 (33.2, 33.5)	33.4 (33.2, 33.5)
Specificity	94.1 (94.1, 94.2)	94.1 (94.1, 94.2)
Positive predictive value	14.7 (14.6, 14.8)	14.7 (14.6, 14.8)
Negative predictive value	97.9 (97.9, 97.9)	97.9 (97.9, 97.9)
Prevalence	3.0 (2.9, 3.0)	3.0 (2.9, 3.0)
Observations	6,88,349	6,88,349

Suppl. Figure 1: Diabetes measures: Tested, undiagnosed, hidden and extrapolated hidden diabetes among the women and men in India, 2019-21



Suppl. Figure 2: Percent share of hidden diabetes across the states of India, 2020



Suppl. Table 2: Burden and prevalence of hidden diabetes by males and females across the states of India, 2020

States	Adjusted prevalence (%)			Adjusted prevalence (%)		
	Total	Female	Male	Total	Female	Male
Jammu & Kashmir	3.9	4.2	3.7	524	265	258
Himachal Pradesh	7.7	8.3	7.2	567	299	267
Punjab	9	7.9	10	2,703	1,128	1,575
Chandigarh	9.6	9.8	9.4	115	54	61
Uttarakhand	7.9	6.6	9.1	885	361	524
Haryana	7.8	7.1	8.5	2,282	971	1,311
Delhi	6.5	5.6	7.4	1,321	528	793
Rajasthan	5.5	5	6.1	4,341	1,890	2,452
Uttar Pradesh	7.8	6.9	8.7	17,878	7,498	10,380
Bihar	9.6	8.7	10.4	11,624	5,055	6,569
Sikkim	8.6	7.9	9.2	58	25	33
Arunachal Pradesh	7.7	6.3	8.9	116	47	70
Nagaland	7.2	6.8	7.6	157	71	85
Manipur	9.1	7.8	10.3	284	122	163
Mizoram	10.4	8	12.6	125	48	77
Tripura	13.4	12.3	14.5	540	243	297
Meghalaya	9.8	6.9	12.7	320	112	207
Assam	8.9	7.9	9.9	3,092	1,338	1,754
West Bengal	12	12.2	11.7	11,683	5,832	5,850
Jharkhand	8	7.2	8.7	3,028	1,333	1,695
Odisha	9.4	9.2	9.6	4,131	2,080	2,051
Chhattisgarh	6.9	6.3	7.5	2,011	918	1,093
Madhya Pradesh	8	7	9	6,684	2,822	3,862
Gujarat	11.3	10.6	11.9	7,751	3,473	4,278
Dadra & Nagar Haveli and Daman & Diu	12.5	9.7	14.4	72	23	49
Maharashtra	8.8	7.3	10.1	10,817	4,340	6,478
Andhra Pradesh	10.2	10.1	10.2	5,340	2,655	2,685
Karnataka	8.3	7.8	8.8	5,498	2,542	2,956
Goa	12.1	9.1	15.1	188	70	118
Lakshadweep	10.6	8.5	12.5	7	3	4
Kerala	8.6	9.4	7.7	3,026	1,717	1,309
Tamil Nadu	10.6	10.2	11.1	8,078	3,875	4,204
Puducherry	8.8	8.6	9	135	68	67
Andaman & Nicobar Islands	11.5	9	13.6	46	17	29
Telangana	9.4	8.2	10.5	3,507	1,523	1,984
Ladakh	3.6	3.5	3.8	11	5	6
India	8.8	8.1	9.5	1,18,943	53,350	65,594

Suppl. Table 3: Burden and prevalence of hidden diabetes by males and females in rural and urban areas across the states of India, 2020

	Percentage						Burden								
	Urban			Rural			Urban			Rural			Total		
	Total	Female	Male	Total	Female	Male	Total	Female	Male	Total	Female	Male	Total	Female	Male
Jammu & Kashmir	4.1	4.2	4	3.9	4.2	3.6	3.9	3.9	77	86	361	188	173	524	
Himachal Pradesh	7	8.6	5.7	7.8	8.2	7.4	7.7	53	30	23	514	269	244	567	
Punjab	9	7.6	10.2	8.9	8.1	9.7	9	1,108	438	670	1,595	690	905	2,703	
Haryana	8.8	7.1	10.3	7.2	7.1	7.3	7.8	1,033	387	646	1,249	584	665	2,282	
Rajasthan	5.3	4.6	6	5.6	5.1	6.1	5.5	1,091	453	638	3,251	1,437	1,814	4,341	
Uttar Pradesh	7.6	7.3	7.8	7.9	6.7	9	7.8	4,081	1,857	2,224	13,797	5,641	8,156	17,878	
Bihar	11.9	10.5	13.2	9.3	8.4	10	9.6	1,742	727	1,015	9,881	4,327	5,554	11,624	
Assam	12.4	10.6	14	8.3	7.4	9.2	8.9	652	273	379	2,440	1,065	1,375	3,092	
West Bengal	13.8	12.6	15	11	12	9.9	12	4,799	2,121	2,678	6,884	3,712	3,172	11,683	
Jharkhand	9.2	7.7	10.5	7.6	7	8.1	8	894	357	537	2,134	976	1,158	3,028	
Odisha	8.6	9.5	7.9	9.6	9.2	10	9.4	694	367	327	3,437	1,713	1,724	4,131	
Chhattisgarh	7.6	7.3	8	6.6	6	7.3	6.9	583	271	311	1,429	647	782	2,011	
Madhya Pradesh	8.3	7.3	9.1	7.9	6.9	8.9	8	1,975	840	1,135	4,709	1,982	2,727	6,684	
Gujarat	11.7	10.4	12.8	10.9	10.8	11	11.3	3,804	1,585	2,219	3,948	1,888	2,059	7,751	
Maharashtra	10.1	7.5	12.5	7.5	7.2	7.9	8.8	5,954	2,095	3,858	4,864	2,244	2,619	10,817	
Andhra Pradesh	11.4	10.2	12.5	9.5	10.1	9	10.2	2,073	925	1,149	3,267	1,731	1,536	5,340	
Karnataka	8.1	8	8.2	8.4	7.6	9.2	8.3	2,312	1,120	1,192	3,186	1,422	1,764	5,498	
Kerala	8.6	9.4	7.7	8.6	9.3	7.9	8.6	2,080	1,190	890	946	526	419	3,026	
Tamil Nadu	10.9	10.9	11	10.3	9.4	11.2	10.6	4,357	2,177	2,180	3,721	1,698	2,023	8,078	
Uttarakhand	7.5	6.8	8.1	8	6.4	9.6	7.9	291	125	166	594	236	358	885	
Tripura	16.2	14.8	17.5	11.8	10.8	12.8	13.4	234	105	128	306	137	168	540	
Telangana	10.2	8.5	11.9	8.6	7.9	9.3	9.4	1,749	721	1,028	1,758	802	955	3,507	
Andaman & Nicobar Islands	14.2	11.4	16.6	9.4	7.3	11.3	11.5	25	9	16	21	8	13	46	
India	9.8	8.8	10.7	8.4	7.8	8.8	8.8	45,202	19,575	25,627	73,741	33,775	39,967	1,18,943	

Suggested citation

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1. To pilot innovative data collection methods and mainstream successful pilots into larger data collection efforts;
2. To impart formal and informal training to a new generation of data scientists; and
3. To serve as a resource for data stakeholders, including Government data agencies and ministries.

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