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# Urban health challenges in India – lessons learned from a surveillance study in Pune

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#### **Abstract**

Urban health in India is gaining increasing attention due to the growing share of urban population and the changing living conditions caused by the rapid urbanization process. The rising prevalence of non-communicable diseases (NCDs) such as diabetes is partly attributed to this process making NCD prevention and control one of the biggest public health challenges in the 21st century. Though public health programs in India are increasingly targeting NCDs, data quality and availability to budget scarce resources remains a challenge. The objective of the study was to conceptualize a prototype for an urban NCD sentinel surveillance system to capture data on newly diagnosed NCD cases, taking also into account socio-spatial intraurban differences. As preliminary steps, two systematic literature reviews, mapping of healthcare providers and a knowledge attitude practice survey on disease surveillance were conducted. In total, 258 private primary healthcare providers (allopathy, ayurveda, homeopathy and unani) participated in the survey, out of these 127 agreed to participate in the six months surveillance study, providing data on a monthly basis. The study indicates that, despite the small size and low level of infrastructure in the private clinics, these practitioners play an important role in diagnosing and treating NCDs. They can be involved in NCD surveillance, if the following major barriers are addressed: lack of regulation of the private sector, cross-practices among different systems of medicine, limited clinic infrastructure, and knowledge gaps about disease surveillance. Based on our findings, a voluntary augmented sentinel NCD surveillance system including public and private healthcare facilities at all levels of care might be an adequate approach to monitor NCD related health trends.

#### Zusammenfassung

Urbane Gesundheit in Indien gewinnt aufgrund des zunehmenden Anteils der urbanen Bevölkerung sowie der durch den Urbanisierungsprozess veränderten Lebensbedingungen in Städten an Bedeutung. Die steigende Prävalenz nicht-übertragbarer Erkrankungen (NCDs) wie etwa Diabetes wird u.a. diesem Prozess zugeschrieben und macht die Kontrolle und Behandlung von NCDs zu einer der wichtigsten Herausforderungen der öffentlichen Gesundheit im 21. Jahrhundert. Obwohl öffentliche Gesundheitsprogramme in Indien zunehmend NCDs adressieren, behindern die fehlende Datenverfügbarkeit und -qualität eine angemessene Budgetierung der vorhandenen Ressourcen. Ziel der Studie war es, einen Prototypen für ein urbanes NCD-Gesundheitsberichterstattungssystem für die Erfassung neu diagnostizierter NCDs zu konzeptualisieren, das auch räumliche und soziale intrarurbane

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Differenzen einbezieht. Vorbereitend wurden zwei systematische Literaturanalysen, die Kartierung von Gesundheitseinrichtungen und ein Knowledge-Attitude-Practice-Survey zu Gesundheitsberichterstattung durchgeführt. Insgesamt nahmen 258 private Allgemeinmediziner (Allopathie, Ayurveda, Homöopathie und Unani) an dem Survey teil, davon erklärten sich 127 Ärzte bereit, sich an der sechsmonatigen Studie zu beteiligen und monatlich Daten bereit zu stellen. Die Studie zeigt, dass die Ärzte bei der Diagnose und Behandlung von NCDs trotz der geringen Größe und geringen Infrastrukturausstattung der Kliniken eine wichtige Rolle spielen. Sie stärker in die Gesundheitsberichterstattung von NCDs einzubeziehen ist möglich, wenn die folgenden Barrieren abgebaut werden: mangelnde Regulierung des Privatsektors, das parallele Praktizieren verschiedener Medizinsysteme sowie begrenzte Klinikinfrastruktur und Wissenslücken zu Gesundheitsberichterstattung. Basierend auf unseren Ergebnissen wäre ein freiwilliges, unterstützendes Gesundheitsberichterstattungssystem mit ausgesuchten Praxen als Meldestellen für NCDs, das sowohl private als auch öffentliche Gesundheitseinrichtungen aller Versorgungsstufen einbezieht, ein adäquater Ansatz für die Beobachtung NCD-bezogener Gesundheitstrends.

**Keywords** Urban health, public health, disease surveillance, non-communicable diseases, Pune, India

#### 1. Introduction

The rapid urbanization process in many low and middle income countries, especially in Asia and Africa (*UN DESA* 2015), alters living conditions for millions of people and affects their health (*WHO* and *UN-Habitat* 2016; *WBGU* 2016: 199 ff.). Urban environments influence human health in multiple ways – positively and negatively. Different groups of urban dwellers have different capacities for making use of the health benefits cities offer, e.g. health care services or food availability. Likewise the exposure towards the negative health effects (e.g. indoor air pollution) differs significantly within the urban population. Therefore one will find – especially in low- and middle income countries (LMIC) – large health disparities in urban areas (*WHO* and *UN-Habitat* 2010).

#### 1.1 Urbanization dynamics in the city of Pune

The Pune Metroplitan Region, which is located in India in the state of Maharashtra, is exemplary for the rapid, often unsteered growth. Pune (once Poona) is witnessing deep transformation processes since 1991 (Kraas and Butsch 2016). After Indian independence, the city grew remarkably in connection with the city's regional and agricultural embedding, the national policy for the diversification of industries and the existing renowned educational facilities. Today, Pune is India's eighth largest urban agglomeration (ninth largest municipality) with 5.1 million inhabitants in 2011 (Census 2011). Situated 160 km east of Mumbai as the country's largest and economically most important city, Pune in the past used to offer less business

opportunities and was comparatively less connected to global processes. Instead, it offered a higher quality of life and was a place for those escaping Mumbai but still wanted to stay connected (e.g. pensioners).

Remarkable growth since 1991 brought about deep changes to the city, which was dominated mainly by its universities and the military being the seat of the Indian Army's Southern Command. Today, Pune has a diverse economic structure and a well connected infrastructure. It is part of a larger urban development corridor stretching from Ahmedabad via Mumbai to Pune (Shaw 1999). Within the State of Maharashtra, this urban corridor (namely with the districts of Mumbai, Thane and Pune) shows highest values of the Human Development Index (UNDP India 2014). The future plans envisage an integration into the Delhi-Mumbai industrial corridor with an infrastructural upgrade and the creation of a large industrial zone at node No. 19, the Pune-Khed industrial area (PMC 2012).

The pace of these demographic and economic developments has overstretched the municipality's planning capacity and has caused tremendous changes in the physical (e.g. land use changes, degradation of the urban infrastructure, increasing environmental pollution and aggravated heat island effect) and the social (e.g. changing eating habits, altered working conditions, increase in the pace of live, increasing socio-economic disparities) urban environment (*Kroll* 2013; *Pandey* 2009). New gated housing societies and prestigious townships with own infrastructure services (e.g. 24/7 provision of water and electricity, health care facilities and schools), shopping malls and

business complexes stand as symbol for the massive fragmentation process that is currently affecting the city (*PMC* 2012). At the same time, 353 declared (legal) and 211 undeclared (informal) slums are located within the city, hosting 41% of the population (*PMC* 2012).

The liberalization of the Indian economy also affected the health care system. In Pune, a large number of private health care facilities emerged especially since the year 2000 and many private facilities have grown in size and increased their services (Butsch 2011). Therefore, medical treatment in line with international standards is available in several private hospitals. Public health care services, once intended to serve as the regular source of care in India, has not been able to keep pace with the city's growth. Capacity problems and shortfalls in the provision of consumable supplies impede public facilities - though having highly qualified personnel - to deliver adequate treatment. Private providers stepped into this gap but often demand charges beyond the economic capacity of large sections of the society. Additionally, some of the treatment procedures like over-diagnosis, over-treatment or inadequate medication have to be addressed as unethical. In this situation, access to health care services - understood as the utilization of adequate services - is difficult for many Puneits (Butsch 2011). Furtermore, the health care sector is very heterogenous with different practitioners following different systems of medicine: allopathy ("western medicine") and traditional systems of medicine such as ayurveda, homeopathy and unani.

# 1.2 The challenge of non-communicable diseases in urban India

Changing living conditions and lifestyles as well as population ageing are leading to an epidemiological transition with an increasing morbidity and mortality through non-communicable diseases (NCDs) in Pune (as well as in other Indian cities) (*Kroll* et al. 2014 for Pune; *Rajan* and *Prabhakaran* 2012 for urban India). NCDs are chronic conditions with rather slow progression and are rarely completely curable. The four most common NCDs (cardiovascular diseases, cancers, chronic respiratory diseases and diabetes) are, amongst other factors, mainly caused by preventable behavioural risk factors such as tobacco and alcohol consumption, unhealthy diet and insufficient physical exercise (*WHO* 2014a). Though NCDs are not confined to cities, urban environments stimulate lifestyles and

behaviours that can act as risk factors for NCDs (*WHO* and *UN-Habitat* 2016). NCDs also impact people in India at younger ages compared to high income countries, increasing the healthy life years lost and the risk of premature death (*WHO* 2014a; *WHO* 2014b).

NCDs have a huge socio-economic impact on the affected households due to required long-term treatment. Since healthcare in India is mainly financed by out of pocket expenditure, it is particularly difficult to bear for the urban poor (Rajan and Prabhakaran 2012). This increases the risk of inadequate disease control and promotes comorbidities (e.g. diabetic foot, organ damage and communicable diseases such as tuberculosis) (Gupta et al. 2011, Harries et al. 2015; WHO 2014a). Therefore, the increasing prevalence of NCDs also jeopardizes communicable disease prevention and control (WHO and UN-Habitat 2016). It also strains the already overburdened public healthcare system, which will also require reorientation to address these newer challenges with referral linkages, follow-up systems and clinical guidelines for NCD treatment (Mohan et al. 2011). Given their devastating health and socio-economic effects, the increasing burden of NCDs is considered as one of the most pressing global public health challenges (UN 2012; WHO 2013). The WHO (2013: 4) has identified six objectives to fight NCDs, in short: raising priority on prevention and control, strengthening national capacity for NCD control, reducing modifiable risk factors, strengthening health systems, promoting research and monitoring the trends and determinants of NCDs and evaluating progress in prevention and control.

Despite the increasing impact of NCDs on public health in India, a routine health care facility based NCD surveillance sytem is missing. The objective of disease surveillance is to address a defined public health problem and to develop evidence-based measures to protect and promote population health (Hall et al. 2012). The inadequate availability and quality of mortality, morbidity and risk factor data hampers the planning process for NCD prevention and control in India (Mohan et al. 2011; Raban et al. 2012; World Bank 2011). Traditionally, the main focus in public health has been on surveillance of communicable diseases such as malaria, dengue or tuberculosis. Furthermore, data is mainly collected from public healthcare facilities despite the dominant role of the private healthcare sector in cities: in India, general private practitioners provide almost 80% of outpatient and 60% of inpatient care (Reddy 2015), a study in Pune found similar numbers (*Butsch* 2011). Public health programs on NCDs only have weak surveillance components (*Kroll* 2015). Existing data is often not disaggregated according to cities or intra-urban population subgroups. The long-term nature and complex disease aetiology of NCDs requires a comprehensive and long-term health-system mediated response. Essential to this goal is accurate and sequential data for planning and evaluation through disease surveillance.

Against this background, the objective of the study was to conceptualize a prototype for an urban NCD sentinel surveillance system to capture data on newly diagnosed NCD cases, taking also into account spatial and socio-economic intraurban differences. Based on the factual predominance of private practitioners and their limited involvement in surveillance efforts, the system aimed at making data available from private practitioners providing primary care. The project's main aim was to design and test such a system in three areas in Pune for a six months period and to evaluate its implementation success. As preliminary steps, two systematic literature reviews, mapping of healthcare providers and a knowledge attitude practice survey were conducted. We present the major findings of the different research steps and discuss the major lessons learned.

#### 2. Methodology

The project was based on a multi-method research approach including four major steps (Fig. 1).

#### 2.1 Systematic literature review

Two systematic literature searches (*Khan* et al. 2003) were conducted to capture the state of the art on NCD surveillance approaches and involvement of private healthcare practitioners in disease surveillance. For the first review

with focus on NCD surveillance, three databases were searched to identify citations published in English language between 1993 and 2013. In total, 20 manuscripts met inclusion criteria (*Kroll* et al. 2015). For the second review on private practitioner involvement in surveillance, four databases were searched to identify peer-reviewed and gray full-text documents in English with no limits for year of publication or study design. Forty manuscripts were reviewed (*Phalkey* et al., manuscript under review).

#### 2.2 Selection and mapping of reseach areas

A comprehensive healthcare facility list with location, system of medicine and qualification of all practitioners in Pune, which could have been used as denominator for the surveillance study, was not available. Therefore, three research areas were selected: (1) the ward Kasba-Vishrambaugwada<sup>1</sup>, located in the inner city with the maximum of healthcare facilities; (2) the ward Dhankawadi<sup>2</sup>, located at the border of the administrative city area with newer and older neighbourhoods; (3) Pirangut and the adjacent village Lavale<sup>3</sup>, located outside the limits of the Pune Municipal Corporation (PMC), belonging to the rapidly urbanizing urban fringe of Pune. The areas depict different phases of the urbanization process and therefore face distinct infrastructural, demographic and environmental challenges with respect to health determining factors and health services.

Healthcare facility mapping was carried out with Mobile Mapper 6W/GIS with the aid of an administrative map of Pune obtained from PMC. Information on type of clinic, system of medicine and speciality was recorded in a standardized way, other information such as contact number and opening hours were noted if available. Data were fed into a database, along with the GPS coordinates. The coordinates of the clinics were then plotted on Google Earth, from where they were imported to Quantum GIS and converted to (.shp) shape file and overlaid on Google Street Map, which was then used as a guide during the following survey.

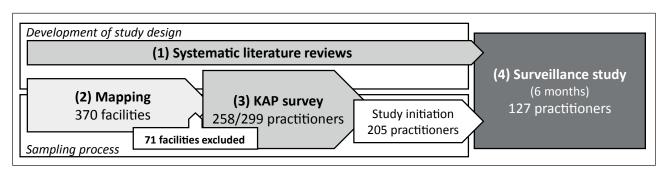


Fig. 1 Project steps: Development of study design and sampling process

#### 2.3 Knowledge attitude practice-survey

A knowledge attitude practice (KAP) survey regarding health surveillance activities among the medical practitioners was conducted in the three research areas (full sampling). The semi-structured questionnaire consisted of five sections: (1) demographic information about the respondents, (2) infrastructure in the clinic, (3) diagnostic routines for six selected diseases and the availability of in-house laboratory facilities, (4) assessment of the respondents' knowledge about disease surveillance and their attitude toward data recording and reporting, (5) probing the respondents' interest in participating in a NCD surveillance system. Each clinic was visited during opening hours. In clinics with more than one practitioner, only the head was included in the survey. Mandatory informed oral consent was obtained from all willing participants.

#### 2.4 Surveillance study

Based on the previous three steps, a design for a sentinel surveillance system to capture ten first-time diagnosed NCDs (diabetes, hypertension, cerebrovascular diseases, ischemic heart diseases, asthma, chronic obstructive pulmonary diseases (COPD), breast, cervical, lung and oral cancer) was developed. These conditions were selected according to major causes of death in India (*WHO* 2014b) and based on recommendations by the WHO (2013). Restriction to first time diagnoses was chosen due to the absence of a unique patient ID in order to identify duplication of cases if patients visited additional practitioners for care.

All practitioners who had stated an interest (n=205) were personally approached to explain the study framework of the six months surveillance study and to obtain written consent. Each participant was provided with a paper-based register with a unique facility ID containing 100 reporting forms with the following items: date of visit, age, gender, residential area (on sub-ward level), first time diagnosis for ten diseases, diagnosis confirmation (presumptive or confirmed) and treatment (initial treatment at research unit (RU) or referral at first instance). Since practitioners were hesitant to record income and occupation of the patients (Phalkey et al. 2015), we used educational qualification and residence in slum or non-slum area as two proxy indicators for the socio-economic status of the patient in line with the National Family Health Survey (IIPS 2007). Data were collected on a monthly basis

on site by four researchers using a standard protocol. Standardized participants' feedback about the register and study design was gathered during the first and the sixth data collection. Data were entered into a database after each collection round and validated by two other researchers.

#### 3. Results

#### 3.1 Systematic literature reviews

In the literature review on NCD surveillance (*Kroll* et al. 2015), eleven of the 12 case studies identified were conducted in high-income countries. Eight supporting documents confirmed that NCD surveillance is confined in most low- and middle-income countries despite the increasing NCD burden and its socioeconomic impact. Nine studies were passive assisted sentinel surveillance systems, of which six focused on the primary care level and three had additional active surveillance components, i.e., population-based surveys. Given the complex system requirements, the combination of multiple surveillance approaches can help to increase the range of information for effective NCD surveillance.

The review on private practitioner involvement in surveillance in low and middle income countries (*Phalkey* et al., manuscript in review) shows their limited inclusion. Main barriers observed for adequate reporting were inadequate knowledge, lack of infrastructure at the facility level, complicated reporting mechanisms and unsatisfactory attitudes on behalf of the government. Several studies recommended the provision of periodic training by surveillance program officers, supportive supervision and regular feedback to practitioners in order to improve case notification.

#### 3.2 Mapping

Lack of regulation of the private healthcare sector is a major challenge for urban healthcare in India (*Baru* 2013). Mapping of the clinics was challenging since some were hidden in small alleys (despite checking all areas physically, it cannot be ruled out that some clinics were left out), had no proper sign board, or were permanently or temporarily closed without any notice. Therefore, the information collected on 370 clinics during the mapping exercise had to be verified during the KAP survey, and 71 clinics were excluded due to permanent (n=30) or temporary (n=35)

closure, or irregular or limited (< 6h/week) opening hours (n=6). From all clinics visited during the KAP survey (n=258)<sup>4</sup>, the amount of clinics was the highest in the urban fringe ward (Dhankawadi) (n=128) with majority of the clinics in the northern subwards closer to the city center. The amount of allopathic practitioners was higher in the inner city ward (n=32, 30%) compared to the urban fringe ward (n=21, 16%) (*Table 1*).

#### 3.3 KAP survey

From the 299 practitioners approached to participate in the KAP survey, 258 practitioners agreed (86%). Main reasons for non-participation were lack of interest (n=15, 37%) and lack of time (n=5, 12%). The majority of the respondents were trained in alternative medicine systems (n=199, 77%), whereas 59 practitioners (23%) were trained in allopathy (*Table 1*).

The mean duration of practice was 15.4 years. The majority of the clinics was rather small, headed by a single doctor (n=181, 71%) and without a receptionist (n=107, 41%), with an average of 15 patients per day coming mainly from the same ward (n=168, 65%) and limited clinic infrastructure (*Table 1*). Around 23% of the practitioners (n=59) stated to maintain medical records containing essential surveillance information (age and gender of patient, diagnosis, test results); only 29 practitioners (11%) kept electronical records. Though size and infrastructure of the clinics were similar among the three areas, the inner city ward had a higher number of allopathic, postgraduate and more experienced practitioners, with a larger catchment area of patients.

More than 91% of the practitioners of all systems of medicine said that they diagnosed diabetes, cardio-vascular diseases and chronic respiratory diseases in their clinic; though referral of cases was higher among ayurvedic and homeopathic practitioners. For communicable diseases such as tuberculosis, the share of allopathic practitioners diagnosing and providing treatment within their clinic was higher compared to ayurvedic and homeopathic practitioners (*Table 1*). Every second respondent diagnosing dengue fever and tuberculosis as notifiable diseases at his or her clinic (n=101, 52%) said that they reported new cases to the city administration.

Overall knowledge about surveillance was low. Only 24% (n=62) of all practitioners were able to name at

least two out of four disease surveillance functions as identified by the World Health Organization (data collection, analysis, dissemination and application) (*M'ikanatha* et al. 2013). One third (n=94, 36%) of the practitioners could name at least two national disease control programs that require reporting from the private sector. Knowledge was better among allopathic practitioners. Despite the limited awareness and practice, the majority of the practitioners (n=195, 76%) had a positive attitude about participating in routine surveillance. When asked about their interest to participate in a six months NCD surveillance study, 70% of the respondents (n=180) were interested, 10% (n=25) undecided.

#### 3.4 Surveillance study

From 205 practitioners approached for the surveillance study, 127 (49% of all KAP participants) gave written consent for participation in the surveillance study (Table 2). Thirteen practitioners (10%) dropped out during the study, mainly due to lack of time (n=3, 23%) and frequent absence (n=3, 23%). Case reporting remained constant and varied between 1.3 to 2.6 newly diagnosed cases per practitioner per round. Whereas the average number of cases per practitioner per round was the highest among allopathic practitioners (17.4), the absolute maximum of cases during the six months study was submitted by traditional medicine practitioners (n=895, 70%) (Table 2) who were the majority in all three areas. However, the individual reporting behaviour varied considerably and was often not linked to the system of medicine. The majority of practitioners (n=63, 50%) submitted one to ten cases during the six months study, 22% (n=28) of all practitioners did not submit any case. Main reasons given for low reporting were pure ayurvedic or homeopathic practice (only providing additional NCD treatment) (n=25, 43%), non-reporting of cases due to negligence (n=17, 29%) and low number of patients or irregular opening hours (n=5, 9%).

In total, 1,532 first-time diagnoses of the ten conditions were reported in 1,283 individuals, with multiple conditions reported in 224 (18%) patients. The share of diseases diagnosed by practitioners with different systems of medicine was similar (*Table 2*). The majority of the cases was laboratory confirmed (n=1,109, 72%) and treated within the clinic (n=953, 74%). Referral was higher among ayurvedic and homeopathic practitioners. One fifth of all cases (n=315, 21%) was treated within the clinic based on presumptive diagnosis, which increases the

Table 1 Major findings from the KAP study (own survey, n=258) (n (%))

		Allopathy (59)	Ayurveda + Unani⁵ (114)	Homeo- pathy (85)	TOTAL (n=258)		
General information about clinic/practitioner							
Location	Inner city ward	32 (54)	48 (42)	27 (32)	107 (41)		
	Urban fringe ward	21 (36)	57 (50)	50 (59)	128 (50)		
	Sub-urban fringe area	6 (10)	9 (8)	8 (9)	23 (9)		
Qualification	Graduate	29 (49)	96 (83)	67 (79)	192 (74)		
	Postgraduate	30 (51)	18 (16)	18 (21)	66 (26)		
Duration of practice	Total mean (SD)	23.1 (12.4)	14.3 (11.2)	12.0 (8.3)	15.4 (11.4)		
Patients per day	Mean (SD)	25 (25)	22 (17)	12 (8)	15 (11)		
Catchment area	Majority same ward	32 (54)	78 (68)	58 (68)	168 (65)		
Clinic infrastructure	2						
Logistics	Computer	27 (46)	44 (38)	30 (36)	101 (39)		
	Internet	28 (48)	48 (42)	39 (46)	115 (45)		
	Medical records (age, gender, diagnosis, test results)	16 (27)	19 (17)	24 (28)	59 (23)		
Human resources	Receptionist	42 (71)	38 (33)	27 (32)	107 (41)		
Diagnostic tools	ECG	21 (36)	21 (18)	17 (45)	59 (46)		
	Laboratory	13 (22)	13 (11)	11 (13)	37 (14)		
Treatment	In-patient admission	19 (32)	18 (16)	16 (19)	53 (20)		
Diagnostic and treatment practice							
Diabetes	Diagnosis	58 (98)	109 (96)	78 (92)	245 (95)		
	Laboratory confirmation	52 (90)	99 (91)	73 (94)	224 (91)		
	Treatment in clinic	45 (78)	58 (53)	46 (59)	149 (61)		
Tuberculosis	Diagnosis	53 (90)	76 (76)	60 (71)	189 (73)		
	Laboratory confirmation	45 (85)	50 (66)	53 (88)	148 (78)		
	Treatment in clinic	38 (72)	21 (28)	18 (30)	77 (41)		
Knowledge and opi	Knowledge and opinion regarding surveillance efforts						
Knowledge – Able	2 of 4 surveillance	24 (41)	21 (18)	17 (20)	62 (24)		
to name at least	components		, <i>,</i>				
	two national disease control programs	25 (42)	38 (33)	31 (36)	94 (36)		
Opinion	Current NCD burden is not adequately captured	44 (75)	66 (58)	50 (59)	160 (62)		
	Disease surveillance is important for urban health	54 (93)	106 (93)	80 (95)	240 (94)		

risk of wrong treatment. Overall, 29% of all cases (n=345) were diagnosed in patients younger than 40 years, supporting existing assumptions of an early onset of NCDs as described in the literature for urban India in general. COPD was more often reported in patients with low level of education. Furthermore, the share of patients without formal education or primary degree was the highest among homeopathic practitioners (n=134, 45%), whereas the share of patients with a graduate or postgraduate degree was the highest among allopathic practitioners (n=338, 48%).

With respect to data quality, in 285 forms (22%) at least one value was missing, mainly education (n=70, 7%), diagnosis was missing only on 2 forms. Complete recording of all newly diagnosed patients during the six months was – according to own assessment by the practitioners – claimed by 28% of the practitioners; in total 64% of practitioners (n=73) entered at least 75% of all cases (*Table 2*). Accuracy of information was difficult to assess due to lack of secondary data; further, lack of standardised case definitions for the selected

diseases impact the quality of data. It was observed during the monthly data collection, that practitioners sometimes filled the register during data collection based on own records, laboratory tests or on memory. This increases the risk of wrong data and underreporting. Practitioners seemed to be reluctant to ask patients for educational degree and slum/non-slum residence and the information on residence seemed to be biased: for example, in some cases practitioners stated slum residence in a subward where the city slum atlas (MASHAL 2011) indicated that no slums existed. Due to the possible misclassification bias, residence was not included in the results.

After the final data collection, 91% of the practitioners (n=104) were of the opinion that the study design was in principal transferable to the whole city, and 93% of the practitioners (n=106) said they would be willing to participate in a routine NCD surveillance system, based on their experience in the study. Out of these, 64% (n=7) would be willing to send data electronically, either through computer or smartphone-based applications.

*Table 2* Major findings of the surveillance study (n (%))

	Allopathy	Ayurveda	Homeopathy	Total				
Number of Reporting Units (RUs) and drop outs (n=127)								
No. of RUs	25 (20)	58 (46)	44 (35)	127 (100)				
No. of drop outs	5 (20)	5 (9)	3 (7)	13 (10)				
Average and total number of cases per RU per collection round (n=127)								
No. of cases	388 (30)	582 (45)	313 (25)	1283 (100)				
Ø cases/RU	17.4	10.2	7.4	10.6				
Average no. of submitting RUs	12.2 (49)	23.7 (41)	15.8 (36)	51.7 (41)				
Self-evaluation: completeness of recording (6 months) (n=114)								
75% to 100% of all cases	14 (70%)	33 (62)	26 (64)	73 (64)				
Below 50% of all cases	0	8 (15)	6 (15)	14 (12)				
Five most frequently diagnosed conditions (n=1532)								
Hypertension	193 (42)	273 (40)	156 (40)	622 (41)				
Diabetes	127 (28)	223 (32)	110 (29)	460 (30)				
Asthma	78 (17)	80 (12)	52 (14)	210 (14)				
Ischemic heart diseases	16 (4)	41 (6)	24 (6)	81 (5)				
COPD	15 (3)	32 (5)	29 (8)	76 (5)				

#### 4. Discussion

The four project stages reveal several barriers, but also opportunities for involving private healthcare practitioners in NCD surveillance in order to improve data availability and quality for NCD prevention (e.g. awareness programs) and control (i.e. improved access to adequate care and longterm treatment).

#### 4.1 Opportunities

The KAP survey and the surveillance study indicate that private allopathic and traditional medicine practitioners at the primary healthcare level diagnose and treat NCDs within their clinics. Therefore their exclusion from routine NCD surveillance would lead to a bias in case sensitivity. The systematic literature review reveals that existing NCD surveillance systems (e.g. Canadian Primary Care Sentinel Surveillance System) include or are even only based on primary healthcare providers. Furthermore, the literature review and the surveillance study show that patients are often not referred to specialists unless complications arise (*Kroll* et al. 2015; *Kroll* et al. 2016).

The surveillance study indicates that people of lower socio-economic status prefer alternative medicine practitioners, one reason probably being their lower fees. Therefore, exluding ayurvedic and homeopathic practitioners would lead to case ascertainment bias, i.e. the effectiveness for identifying cases would not be the same for all population subgroups such as urban poor or migrants with reduced access to the formal healthcare system.

Overall, the positive response rate of the KAP survey and the surveillance study, the positive process evaluation of the surveillance study with a low drop-out rate, acceptable respondent cooperation, reporting consistency and data qualiy, and the positive study evaluation shows that private practitioners can be involved in NCD surveillance.

#### 4.2 Barriers

The limited infrastructure in the clinics, especially limited medical record keeping practices, lack of electronic medical records and limited availability of skilled clinic staff, is an important barrier to routine surveillance, since data cannot be automatically ex-

tracted from existing records, but have to be entered in paper-based or electronic forms.

The involvement of private practitioners, especially of the primary healthcare level, in disease surveillance, is difficult in Pune - and other cities in India - due to its vast heterogeneity with different systems of medicine and qualifications, intransparent specializations (e.g. practitioners with a degree in general medicine but a specialization on gynaecological problems), and lack of continuity (e.g. frequent changes in clinic locations, irregular hours of operation and periods of absence). A common registration platform with basic information about the healthcare providers, as envisaged by the Clinical Establishments (Registration and Regulation) Act, 2010 act (Department of Health and Family Welfare, Government of India 2015), is an important prerequisite for their involvement in surveillance and also their regulation.

The overall knowledge about surveillance and health programs requiring reporting from the private sector, as assessed during the KAP survey, was poor. Though around half of the practitioners said they would report mandatory cases of dengue fever and tuberculosis to the Municipal Corporation, this might be overreporting due to social desirability bias. Even during the surveillance study, the observed understanding and commitment by the practitioners varied. Knowledge and awareness was better among allopathic practitioners. Inadequate knowledge was also identified as most important determinant for case detection, confirmation and notification in the literature review on the private sector. An important facilitator is therefore to strenghten surveillance and public health knowledge among healthcare practitioners of all systems of medicine, e.g. in graduate and undergraduate courses and the Continued Medical Education (CME) program.

The relationship between the private and the government sector is also an important influencing factor for reporting behaviour on the side of the medical practitioners. Major points of concern were time consuming reports coupled with complicated and intransparent reporting structures and unclear usage of data, legal issues (e.g. for alternate practitioners where allopathic treatment of diseases is a legal greyzone, or problems of incomplete case reporting if patients do not show up after having been referred to a laboratory for disease confirmation) and the tendency to blame the private sector as scape goat (e.g. not reporting communicable diseases in time).

#### 4.3 Suggested framework for NCD surveillance

The literature review on NCD surveillance suggests that the sentinel approach is globally increasingly applied to monitor NCDs since reporting of NCDs is often not mandatory and complete case detection not required. This approach would help to detect trends signalling changes in the occurrence of the selected NCDs (e.g. co-morbidities, treatment outcomes, disease onset), provide estimates about the magnitude of the morbidity, permit assessment of the effects of control measures and could also lead to improved clinical practice by the healthcare providers serving as sentinel sites (Klaucke et al. 1988). A sentinel system which also takes into consideration socio-spatial aspects would also allow for an intraurban differentiation of health status. This would make it possible to design more targeted interventions, also in urban development.

Findings from the review also indicate that the primary care level is adequate for the selection of reporting units since general practitioners manage a large part of patients particularly in LMICs. Since there is currently no reporting obligation regarding NCDs in India, voluntary reporting of selected sentinel sites would be an appropriate approach. Careful selection and stratification of appropriate reporting units – e.g. according to geographic distribution, socio-economic or demographic status of people in different areas, clinic type, availability of computer and commitment to participate – ensures data validity.

Furthermore, data availability or willingness to install and use one standardized electronic medical record (EMR) system could also be an important selection criterion. Lack of medical records, especially in electronic format, is a major gap at the primary healthcare level in many LMICs. The accuracy, quality and standardization of data are also major hindrances at this level. Against this background, the setup of a sentinel network among volunteering clinics using a single, standardized EMR system would be a solution. This would not only increase data quality and completeness of reporting, but would also improve data keeping practices and improve follow-up of long term treatment plans. Last but not least, it could also have spill-over effects to other clinics.

An augmented system, which seeks regular interaction with the sentinel sites, is an important facilitator to encourage reporting and to improve the relation-

ship between the private sector and the government. Measures could involve training, physical visits for problem solving and quality checks, meetings and workshops, regular surveys among participating practitioners to check on the reporting format etc. Providing minor incentives such as points within a credit system providing benefits, alleviated access to support systems, free training and access to scientific journals and books may also help. The Health Department in Switzerland (Federal Office of Public Health n.y.) for example offers free laboratory tests for selected diseases in laboratories owned by the Health Department as an incentive for its reporting units. Overall, sentinel sites should see a clear outcome of their efforts (e.g. in regular reports) in order to develop ownership.

The review shows that problems do not only exist at the reporting level, costly duplications, inefficiencies and inconsistencies between institutions in the collection, storage, analysis of data and timely reporting are also major problems (*Macfarlane* 2005). A comparatively smaller sentinel network with standardized data could help to overcome also these challenges.

#### Data content

Vital information for NCD surveillance are basic patient demographics and diagnosis. In case of EMRs, disease detection algorithms could be applied to identify cases; alternatively, standardized diagnostic criteria can also be used. Case definitions for NCDs should also take into account different systems of medicine with different diagnostic procedures; however, cross-system practice among alternative medicine practitioners is also a challenge and a system would have to capture how the diagnosis was made. Since practitioners at the primary level do not necessarily have the diagnostic instruments to diagnose all NCDs, presumptive cases should also be recorded. Therefore, a clear definition between presumptive and laboratory confirmed diagnosis is required.

Furthermore, a denominator is necessary to assess the magnitude of a health event. As the literature review shows, one major challenge for data analysis in facility-based surveillance is the availability of an appropriate denominator (*Kroll* et al. 2015). In our surveillance study, we were not able to collect a denominator due to ethical concerns (the total number of patients per clinic is considered as tax sensitive information); therefore usage of data was limited. One

solution is the calculation of morbidity rates based on the number of consultations per practitioner. Additionally, data on NCD risk factors (e.g. weight, smoking, eating habits, family history), comorbidities and treatment outcomes should be included in a system. The latter requires a unique patient ID to continuously add information to a reported case. According to the review, data on comorbidities and NCD risk factors are rarely collected as default data since data are often received from non-standardized EMRs.

A challenge remains the inclusion of socio-economic variables into a surveillance system, which are often missing in many existing surveillance studies (Alwan et al. 2012) as shown by the review. Data was often not linked to socio-economic information and therefore did not facilitate the assessment of health disparities. Nolen et al. (2005) identified the following four general equity stratifiers: (1) socio-economic position (measured through household wealth or assets; education or occupation are good indicators for socio-economic position but no proxies for income or wealth), (2) gender, (3) ethnicity (religion, language spoken, migration background etc.), and (4) geographical area (urban vs. rural, better vs. worseoff areas). In our surveillance study, we used educational qualification and slum or non-slum residency as proxy indicators for the socio-economic status of the patient in line with the National Family Health Survey which is conducted every few years by the Ministry of Health and Family Welfare (IIPS 2007). Univariate measures are insufficient to assess socio-economic status (Kolenikov and Angeles 2009) and residence in slum or non-slum area is a weak proxy due to status inconsistencies. However, the exposure to risk factors differs between slum and non-slum areas (e.g. indoor air pollution for COPD/asthma). We realized during the study, that practitioners were reluctant to ask the patient for this information and data was biased, e.g. slum residence was recorded for patients which were living in slum-free areas according to the Pune Slum Census.

Geographic Information Systems (GIS), which are sometimes used in communicable disease surveillance for outbreak control, can also be a helpful tool for the documentation and analysis of the spatial distribution of disease patterns and risk factors (*Yiannakoulias* et al. 2009). However, the availability of spatial data is a limitation in India as in many LMICs (*Yiannakoulias* et al. 2009). The consideration of small administrative areas (e.g. sub-ward level) instead of

accurate address might be a more feasible solution in these cases.

Linking different surveillance approaches

Due to the challenges described above to collect socio-economic and longitudinal data, and due to the inequities in access to healthcare in Pune, a sentinel facility-based system should be linked to other health or administrative data (e.g. census, surveys) through unique patient identifiers (if existent) or at least small area identifiers (e.g. pin codes). Community-based surveys - which can also be linked to the patients' records - can be used to obtain more patient specific information on risk factors, healthcare utilization, disease knowledge etc.

#### 5. Conclusions

In view of the increasing disease burden of NCDs, the risk of comorbidities and the long term socio-economic impacts in India, capacities for NCD surveillance have to be strengthened to facilitate evidence-based decisionmaking, to evaluate the success of existing public health programs and to identify upcoming health challenges. A sentinel network with private and public healthcare providers using a standardized reporting system would help generating adequate data to monitor trends (e.g. age of diagnosis, importance of different risk factors, comorbidities and treatment outcomes). Such a sentinel system could be linked to regular community-based surveys to understand how many NCD cases especially among the urban poor go unnoticed, what hinders lower socio-economic strata to access adequate health care or what impedes different population subgroups to adopt healthier lifestyles (i.e. behavioural, social or material/ economic barriers).

Furthermore, awareness building about NCD risk factors and NCD management and the improvement of living conditions in cities, i.e. improving socio-economic conditions of the urban poor, making cities more walkable and providing recreational space to encourage health promoting behaviour, are important prerequisites to fight NCDs. This requires the right mixture of multi-sectoral small scale and large scale interventions for health promotion and NCD control through early detection and treatment.

At the moment, we are lacking information about urban health in India and many other LMICs. Especially an in-

traurban differentiation is not possible with the data at hand. In order to make the cities of Asia and Africa, which are expected to host 73% of the global urban population in 2050 (*UN DESA* 2015), healthier places, this information is needed urgently in order to adequately allocate sparse ressources. Single phased studies throw temporary spotlights into the darkness, but continuous surveillance efforts are required to understand epidemiological transitions in the quickly transforming urban agglomerations. In the end political will is needed to make cities healthy (or at least less unhealthy) – and to continuously provide the funds to do so.

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#### **Notes**

- <sup>1</sup>The ward covers an area of 500 ha, is divided into 13 subwards and has a total of 12 slum pockets. The population during the last census (2011) was 222,684 (*PMC* 2012).
- <sup>2</sup>The ward covers an area of 1084 ha, is divided into 9 sub wards and has 6 registered slum pockets. The population during the last census (2011) was 236,621 (*PMC* 2012).
- <sup>3</sup>Pirangut and Lavale are located in the sub district of Mulshi around 23 km from Pune city center. Pirangut has a population of 6,040 inhabitants, Lavale 4,211 inhabitants (*Census* 2011).
- <sup>4</sup>Validated information regading the clinics (i.e. system of medicine) is only available for the 258 KAP participants.
- <sup>5</sup>Three unani practitioners participated in the KAP survey; for the purpose of analysis we combined the data for the three unani practitioners with the ayurvedic practitioners.

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