Postcode based participatory disease surveillance systems : a comparison with traditional risk-based surveillance and its application in the COVID-19 pandemic

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Abstract

Background: The SARS-Cov-2 infection has rapidly saturated health systems and traditional surveillance networks are finding hard to keep pace with its spread. We designed a participatory disease surveillance (PDS) system, to capture symptoms of Influenza-like illness (ILI) to estimate SARS-CoV-2 infection in the community.

Objective: While data generated by these platforms can help public health organisations find community hotspots and effectively direct control measures, it has never been compared to traditional systems.

Methods: A completely anonymised web based PDS system, www.trackcovid-19.org was developed. We evaluated the symptomatic responses received form the PDS system to the traditional risk based surveillance carried out by the Bruhat Bengaluru Mahanagara Palike over a period of 45 days in the South Indian city of Bengaluru

Results: The PDS system recorded 11062 entries from 106 Postal codes. A healthy response was obtained from 10863 users while 199 (1.8%) reported symptomatic. Subgroup analysis of a 14 day symptomatic window recorded 33 (0.29%) responses. Risk based surveillance was carried out covering a population of 605,284 with 209 (0.03%) individuals identified symptomatic.

Conclusions: Web PDS platforms provide better visualisation of community infection when compared to traditional risk based surveillance systems. They are extremely useful by providing real time information in the extended battle against this pandemic. When integrated into national disease surveillance systems, they can provide long term community surveillance adding an important cost-effective layer to already available data sources.

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Introduction

The severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) infection and the associated coronavirus disease 2019 (COVID-19) has assumed pandemic proportions affecting individuals in over 190 countries across all continents except Antarctica. [1] Considering the alarming spread of infection and severity of the disease, the WHO declared the COVID-19 outbreak as a pandemic on March 11, 2020. [2]

The first confirmed case of COVID-19 in India was reported on January 30, 2020 from Kerala, a south Indian state in a medical student who returned from Wuhan, China. [3] Subsequently the disease has spread to the entire country, necessitating the Government of India to declare a complete lockdown from March 25, 2020, to prevent community spread of infection and buy time for the preparedness of health care services. As on May 23, 2020, India had reported 125,000 cases and 3700 deaths.[4] With the pandemic rapidly spreading, approaches to obtain population-based evidence are needed. [5] [6]

Monitoring of an influenza pandemic relies on a number of surveillance sources. The WHO recommends two main variables - the number of laboratory-confirmed cases and the percentage of patients with influenza-like illness visiting sentinel general practitioners. [7] In India due to the fragmented health system and absence of data from general practitioners, traditional contact tracing methodology which has stood the test of time to eradicate smallpox and polio has been put to use extensively in the course of this pandemic. The strong network of frontline Indian Health care workers – Accredited social health activists (ASHA), Anganwadi Workers (AWW), Auxiliary Nurse Midwifes (ANM), Link Workers with health professionals, residents, interns of medical colleges have provided round the clock service in achieving this feat, unheard of in the western world. COVID-19 suspects are manually traced, tested and isolated with their movement closely monitored for 14 days. Their primary (household/close contacts) and secondary contacts (other than household contacts) are home / Institutional quarantined depending on high risk or low risk. [8] This places the surveillance teams at a high risk of exposure to SARS-CoV-2 infection.

Real-time tracking of infectious diseases with use of information technology and big data is still not a priority in most developing countries, and the potential of participatory disease surveillance / crowdsourcing technologies are yet to be tapped. The increase in worldwide internet availability, combined with patient-driven healthcare, has created new possibilities for the development of innovative surveillance systems. [9-11] Participatory disease surveillance (PDS) is an innovative tool for surveillance of communicable diseases in which people are actively encouraged to self-report symptoms or events to help public health experts for appropriate public health intervention. [12]

Expansion of surveillance capacity is required for the COVID-19 pandemic as routine surveillance capacities are overwhelmed. Such novel systems have been used to monitor trends and predict influenza outbreaks across the world. [13,14] These technologies have been applied to the pandemic with similar systems implemented by the Boston Children’s Hospital in the United States of America (https://www.covidnearyou.org/), and King’s College in the United Kingdom [15] (https://covid.joinzoe.com). Social Media giant Facebook in association with Carnegie Mellon University Delphi Research Center, USA is also generating a symptom map across the United States to predict the burden on the health care system. (https://covid-survey.dataforgood.fb.com). The biggest concern about self-reporting apps is under or over-reporting, thus doubting the reliability of the information provided. [12,16]

To address these concerns, we rapidly prototyped and developed, a self-reporting system to track the coronavirus pandemic and compared the responses received by the PDS system to traditional risk based surveillance undertaken in the South Indian city of Bangalore.

Methodology :

Participatory disease surveillance

A crowdsourced, self-reporting symptom tracker was rapidly prototyped and developed to capture and map individual data points with the granularity of postal code. Users self-report the presence or absence of common symptoms associated with the SARS-CoV-2 infection (fever, cough, shortness of breath, sore throat) and probable exposure to a SARS-CoV-2 positive patient in addition to demographics which include age, sex and postcode. An email address is optional to receive updates. The system was designed to process Postal codes of India, USA, UK, Canada and Australia.

The users' postcode was converted to latitude and longitude by the Google Geolocate API [17], thus avoiding any privacy issues related to tracing individual users. While symptomatic and healthy data was crowdsourced, confirmed positive cases could only be added by the administrator after confirmation of cases from Local health bodies. This enabled us to prevent misreporting and spreading panic among users due to erroneous reporting of confirmed positive cases. Healthy, symptomatic and confirmed positive cases were marked as Green, Red and Black circles proportion to the number of cases on the base map layer provided by Openstreetmap.org (https://www.openstreetmap.org/) using the Leaflet Map API (https://leafletjs.com) (Figure 1). The user was provided with an option to modify/edit his data using Postcode and the unique alphanumeric code generated at the end of the submission. This provided an opportunity to change status from healthy to symptomatic and vice versa. Disclaimer regarding data privacy and terms of usage were recorded before the entry of data. Symptomatic cases were removed from the system at the end of 14 days. This was done to have a real time visualisation of cases as the SARS-CoV-2 infection has the highest transmissibility in the first 14 days of infection. [18]

For the purpose of this study, we analysed data gathered from Bengaluru (Postcodes 560001-560110), the capital district of Karnataka in South India, recorded from April 1, 2020 to May 15, 2020. With a population of 13 million, it is the Silicon Valley of India and is the fastest-growing metropolitan city. Confirmed positive cases by Ward was obtained from the daily bulletin of the Bruhart Bengaluru Mahanagapalike (BBMP) website [19] and converted to Postcodes. This data was updated daily as made available by the public body.

Risk-based surveillance by contact tracing

A risk-based contact tracing surveillance was performed on primary and secondary contacts of COVID positive patients between 1st April 2020 and 15th May 2020. This was carried out by the Bruhat Bengaluru Mahanagara Palike (BBMP) in liaison with Medical colleges' of Bangalore in areas with COVID-19 positive cases as per the standard operating protocol issued by the Ministry of Health and Family Welfare, Government of India (MOHFW) [20]. The Medical Officer from the Urban Public Health Centre with his team of Health workers and volunteers visit the households in the area of a diagnosed COVID-19 case. The primary contacts are traced and quarantined. The secondary contacts are informed and advised home quarantine. All houses within 100m radius surrounding the index case, are surveyed and COVID-19 symptoms (fever, sore throat, cold/cough, shortness of breath), history of international travel, comorbidities and contact with COVID-19 cases were elicited. The Government of Karnataka is also using data from telecommunication companies to track the movement of positive cases for a duration of 14 days to identify their primary contacts. [21] Ethical clearance was obtained from Institutional Ethical Board (Kempegowda Institute of

Medical Sciences).

Results

A total of 11062 entries was recorded from 106 postcodes of Bengaluru, in our platform. 10863 of these individuals reported healthy and 199 (1.8%) as symptomatic. Fourteen individuals reported having recovered from their illness during the period. Among the symptomatic responses, 85 (0.77%) reported cough, 42 (0.38%) fever, 62 (0.56%) sore throat and 39 (0.35%) shortness of breath. Eleven had exposure to COVID positive patients and 58 individuals reported as being in self quarantine. The mean age of the cohort was 32.16+- 8.33 years (1-87 years) with 5842 males, and 5220 females. A subgroup analysis of the last 14 days was performed to capture real time symptomatic individuals within one incubation cycle of the corona virus. 33 (0.29%) individuals reported symptomatic during this period . The distribution of data in postal codes of Bangalore are summarised in Supplementary Table 1 and Figure 1

Data from risk-based surveillance was analysed from nine postal codes. A total of 165,379 households were screened over a period of 45 days. 105 health care workers conducted the survey of 165,379 households with a population of 605,284. The surveyed population comprised of 314,787 males and 290,497 females with a ratio of 1.08:1. The average number of individuals per house in the area surveyed was 3.65. 209 (0.03%) individuals were found symptomatic. In the corresponding postcodes, the PDS system recorded 2061 responses with 35 (1.7%) symptomatic. (Table 1) To compare the proportions of symptomatic cases between the two groups, Z – test was applied (p <0.0001). (Table 2)

Post Code	Risk based surveillance (Contact Tracing)				Web based PDS system (www.trackcovid-19.org)		
	Households	Population surveyed	Symptomatic	%	Total responses	Symptomatic	%
560011	7486	29946	10	0.03 %	67	1	1.49 %
560026	35488	157425	91	0.06 %	554	8	1.44 %
560027	15000	30545	5	0.02 %	68	1	1.47 %
560029	48281	135628	34	0.03 %	122	2	1.64 %

560030	10911	48236	30	0.06 %	54	1	1.85 %
560040	11650	58254	11	0.02 %	512	5	0.98 %
560070	7509	30034	3	0.01 %	318	7	2.20 %
560078	18669	74701	1		338	9	2.66 %
560104	10385	40515	24	0.06 %	28	1	3.57 %
Total	165379	605284	209	0.03 %	2061	35	1.70 %

Table 1: Symptomatic individuals in the post codes screen by risk based surveillance. Participatory Disease surveillance (PDS)

Variable		**Participatory Disease surveillance (n=11062)**	**(%)**	**Risk based surveillance (n=605284)**	**(%)**
Gender	Male	5842	52.81 %	314787	
	Female	5220	47.18 %	290497	
Symptomatic	***Total***	***199***	***1.8%***	***209***	***0.03%***
	Fever*	42	0.38%	208	0.03%
	Cough*	85	0.77%	2	0.0003 %
	Shortness* of breath	39	0.35%	2	0.0003 %
	Sore throat*	62	0.56%	5	0.0008 %

Table 2: Comparison between Participatory Disease surveillance (PDS) and Risk based surveillance

*Multiple response

To compare the proportions of symptomatic cases between the two groups Z – test was applied. The result is significant at $p < 0.001$ and value of Z=71.5

Discussion:

The coronavirus pandemic has generated widespread interest in the government and public health agencies to build real-time maps to represent a total number of COVID-19 cases in their region. One dashboard developed by the Johns Hopkins University, Baltimore, has been providing valuable statistics reported by government bodies across the globe.[22] In India, Covid19india.org (https://www.covid19india.org) is a volunteer driven crowdsourced platform that has been providing daily trends and district level case distribution (Source MOHFW) through the pandemic. Though extremely useful at communicating the global pandemic, it provides little information on regional distribution within communities. Districts in India are large, with a mean area of 3,400 sq km (Range 45,652 km^2 - 8.69 km^2) [23] and as the pandemic swells this provides little information to the public or health professionals about the prevalence of disease locally. Individual states have however taken more interest in producing granular data. They have roped in organizations providing Geoinformation systems for public works/agriculture services and have reutilized their services to provide Zone / Taluka / Ward level information for surveillance of the pandemic. However, since all states do not have access to this facility, the reporting has been fragmented and lacks uniformity. These systems have remained one-way communication channels to disseminate information to the public.

To address these concerns a group of doctors and engineers, joined hands to rapidly prototype and develop the trackcovid-19.org platform. The aim was to build a two-way platform to communicate the burden of disease and self-report COVID-19 symptoms at the level of a local community indexed by a postcode. Postcode was chosen to represent clusters as this is the most reliable, reproducible identity the common man can relate to, with a mean area of 82sq km across the country. Aimed at respecting individual privacy, data was represented as clusters of postal codes rather individual locations.

PDS applications using the syndromic approach have found success in tracking the influenza pandemic across the world. [24] In India the Aarogya Setu has been the flagship application developed by the Ministry of Electronics and Information Technology, Government of India has gathered over 90 million downloads in 50 days. It is a digital contact tracing application which tracks the movement of the user using Bluetooth and Global Positioning system (GPS) and sends out a notification if they come in contact with infected people by using its database and algorithms. [25] Despite achieving a large user, it has large gaps in reporting of positive cases with only 1 in 6 cases being recorded. The application relies on positive cases, having used the platform and prompt reporting of the same. Several local governments have also designed and released applications to disseminate local information to their citizens. However, several of these lack regular, timely updates. This fragmented approach has left the user confused and overburdened with many digital tools. Using the right tool across the country, while respecting user privacy to gather appropriate data remains the biggest challenge. [26-28].To address these concerns in addition to participatory layers, our application sourced confirmed positive cases from government databases. This layer remains accurate [29] and ensures prompt dissemination of information to the users of the application. The application currently tracks all reported positive cases in the city of Bangalore and few other Indian cities.

Risk based surveillance v/s Participatory Disease surveillance.

India is currently following risk-based surveillance – the contact tracing approach to address the COVID-19 pandemic. Traditionally it has been used in the control of infectious diseases with low prevalence [30,31] and has been successful in the eradication of smallpox[32], elimination of polio and control of sexually transmitted diseases. [31] This strategy is successful when a limited number of cases need to be traced, and traced individuals can be vaccinated or provided preventive treatment. Once the infection is established and individual clusters can no longer be traced, the usefulness of this strategy to guide control decisions at a community level is diminished, because the cases identified are not representative of the infected individuals in the population. [5] In airborne infections a significant proportion of contacts may be untraceable and additional mitigation measures may need to be applied. Contact tracing may also not keep pace with rapidly spreading pandemics like the SARS-COV-2 no matter how large a proportion of contacts can be traced, thereby reducing its efficiency. [30,31] Due to the dynamics of transmission contact tracing failed to control disease or identify all contacts in the previous Influenza outbreaks. [33-35] This is because contact tracing for influenza is difficult and expensive, even in an outbreak involving a very small population. [31] The success also depends on symptomatic individuals being truthful, skills of the investigator in eliciting information and timing of the survey. These factors may underestimate true disease burden in the population due to underreporting and fear of victimization. Risk-based community tracing can mitigate individual spread but cannot provide a warning or forecast to make informed decisions about the direction of medical resources or the best timing for community testing and control measures.

Participatory surveillance systems are inherently syndromic in approach, dependent on syndrome definitions and reporting behaviour [36] as none of the systems incorporate any laboratory testing. Integration with geoinformation systems can visualise spacio-temporal spread of disease can in real-time. [37] Web based systems have been previously used to estimate the peak H1N1 outbreak in Sweden [7] and data from PDS systems were found to show complementary trends to the incidence of influenza. [12,38] PDS systems can find community hotspots and can then be screened for manual surveillance or community testing measures. (Figure 2) By overlaying multiple layers on the map, governments could use this data to effectively trace, test, isolate cases and open up or lock down communities.. They can be supplemented with software like geographical information systems, disease modelling systems, and other analytical software for real-time analysis of collected data.[39] Foremost among the benefits of participatory surveillance is the ability to conduct large scale, population-based monitoring at low cost. [36] These systems can engage people who may not interact with a health care provider due to inadequate access, resource constraints, or cultural norms. These novel technologies and health surveillance data together estimate the magnitude of health problems and response to outbreaks.[25]

The biggest challenge for PDS systems is user recruitment and retention. Active participation of the government health agencies and partner organizations, with information bulletins, heath education and geo-distribution of disease, which will enhance user interest and retention. In the United Kingdom, the COVID symptom study recruited 3,052,904 participants (4.5% of UK population) and reported symptom rates of 0.4%-2.1% [40] Secondly, the need to Login and provide personal information can refrain users from actively participating. [41] Our system thereby uses a simple structure without the need for any personal identifiable information. It allows the user to modify/edit his data using Postcode and the unique alphanumeric code. Children and the elderly tend to be underrepresented due to technological inability to access such platforms. This was evident in our cohort with a mean age of 32.16 years. Allowing users to report for family members and adding an additional layer of health worker data could mitigate this problem.

Asymptomatic carriers have been found to transmit disease, although their true extent has not been known. [42] Participatory surveillance systems, due to their syndromic approach, cannot detect asymptomatic carriers in the community. Exposure or direct contact with COVID positive individuals can be recorded and testing can be prioritised in regions where clusters of cases are detected. [43] This can effectively help break the chain of asymptomatic transmission in communities.

False reporting of symptoms is a concern amongst decision-makers to trust the data generated by PDS systems during times of a pandemic. The extensive risk based surveillance data available enabled us to compare the two public health approaches. The PDS system picked up more symptomatic individual when compared to traditional risk based surveillance (1.70% vs 0.03%). ($p<0.001$) in both the groups. The proportion of symptomatic individuals was 0.29% in the subgroup of 14 days to account for one incubation cycle of the SARS-CoV-2. This could be explained by the broader reach of this application and openness to share information on a blinded platform. Similar observations were found in Bihar, a northern state in India, where 41,206,440 individuals were screened as a part of the active community surveillance programme accounting for 33.7% of its population (Population of Bihar 2019: 122,256,981). Amongst these 3180 individuals (0.007%) were found to report symptoms of fever, cough or shortness of breath. [44]. The data obtained with PDS systems is real time and continuous, unlike risk based surveillance which is a snapshot of the community and repeated surveillance will require enormous manpower and resources. Through risk based surveillance, more symptomatic individuals can be motivated to get themselves tested in less stressful environment.

Integration into National Disease Surveillance systems.

In India, the Integrated Disease surveillance programme (IDSP) started by the Government of India in 2004, is a decentralized, state-based surveillance program which is intended to detect early warning signals of impending outbreaks and help initiate an effective response in a timely manner, thereby preventing large outbreaks. [45] Since its inception experts have voiced concerns about the need for infrastructure strengthening in the form of adequate training, data management and availability of adequate human resources. [45-48] With healthcare moving to a more patient-driven model [11] and India achieving high rates of internet penetration with the world’s cheapest data [49] web based crowdsourced platforms can quickly strengthen and reduce costs in the IDSP. These digital platforms can also be potentially used in the future by health workers/volunteers to deliver doorstep screening, diagnostic, curative services & implement preventive strategies appropriately. A restrictive testing strategy makes it imperative that data of syndromic reporting is available for the identification and containment of clusters. The entire process will bring community empowerment with no direct physical contact, adhering to the social distancing regulations currently applicable to the COVID-19 outbreak.

Limitations:

In our analysis data from PDS and risk-based surveillance are not from same households though they were located in the same locality, as the study was conducted in the midst of a pandemic. Both risk based surveillance and PDS system were convenience based sampling.

PDS platforms are completely voluntary and require active participation from large proportion of the population to be meaningful and effective. Asymptomatic carriers of infection cannot be picked up by both the discussed modalities and pose the risk of spread. Risk based surveillance may be subject to bias in the reporting of symptoms during due to the fear of COVID-19 subjects being quarantined, compared to using the web-based application.

Conclusion &Recommendation

Postcode based PDS systems can be rapidly developed to provide complementary data sources that help understand disease dynamics when used in tandem with traditional surveillance sources. They are real-time, economical, scalable and epidemiologically appealing. Layering the information with authentic datasets of interest will encourage users to engage and contribute data. When combined with geoinformation systems and analytic models, it can be helpful for policymakers and public health researchers to forecast potential outbreaks and contain them. Integrating into current surveillance systems remains the challenge and can open a new avenue in the containment of communicable diseases across the country.

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Author Contribution: RM was involved in design of study, writeup, revisions. AJ, DB were involved in writeup and revisions. PA, VK were software engineers who developed the web based platform. STV, GG, RTS, RG were involved in risk based surveillance, SR and AH conceptualized and designed trackcovid-19.org as project leads and was involved in manuscript preparation and revisions.

Figure Legends:

Figure 1: Healthy, symptomatic and confirmed positive cases on base map of Bengaluru. Source https://www.trackcovid-19.org (Accessed May 15, 2020)

Figure 2 – A) Representation of a High Risk Community B) Representation of a Moderate Risk Community

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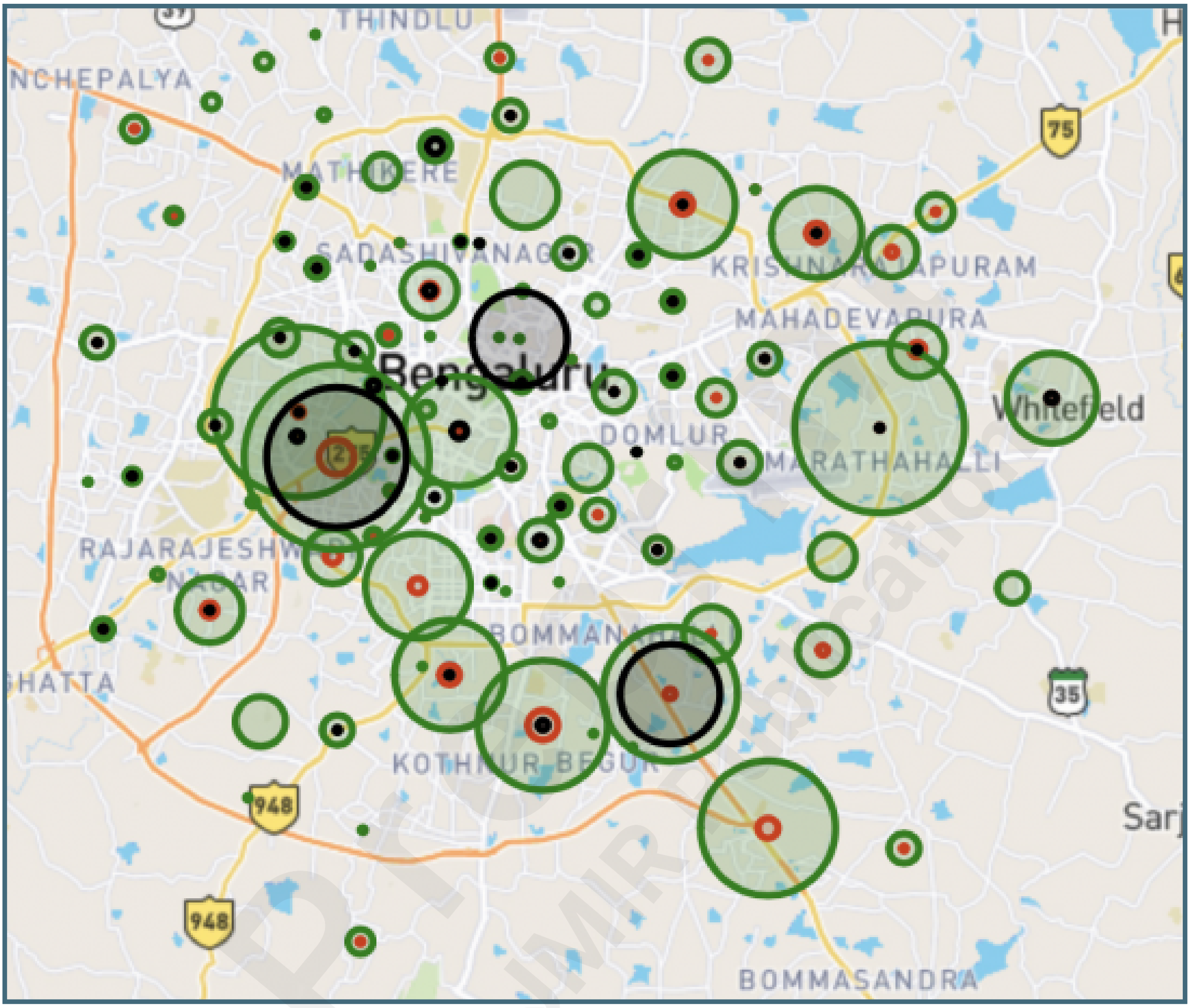
Supplementary Files

Figures

Healthy, symptomatic and confirmed positive cases on base map of Bengaluru. Source https://www.trackcovid-19.org (Accessed May 15, 2020).



A) Representation of a High Risk Community B) Representation of a Moderate Risk Community.