INTERACTIVE TABLES

EPICROWD, Recife, Brazil

Executive Summary

From March 25 to 27, 2015, the city of Recife hosted the first edition of EpiCrowd, an international symposium on digital disease detection and mass gatherings. The event organizers invited 110 participants from various parts of Brazil and 8 other countries, creating a forum for discussion of developments in public health surveillance focusing on the specific theme of new technologies. The agenda of the event included conferences, panels, tech demos and interactive tables, aiming to engage with the audience to promote specific content, and more generally to motivate and encourage the adoption of these innovations in their workspaces.

Of the total of confirmed participants, 94 participated effectively in the event and 162 were on the waiting list. EpiCrowd events streamed online and reached 253 unique users during the 3 days. The Fan Page facebook.com/epicrowd had 232 likes and 9118 people reached through 30 posts. The Fan Page concentrates all the videos of the presentations and updates, serving as a space to exchange experiences with the group.

The interactive tables proved to be an effective way to promote an animated exchange of ideas. Indeed, the tables yielded a wealth of suggestions (see below) to enhance the adapted new app for its use in Brazil and for its participatory strategy in general.

The participants present, those on the waiting list and those watching the webcast constitute a group of professionals who showed interest in the subject and who can be invited to continue to learn, share and promote participatory surveillance and digital disease detection in Brazil.

INTERACTIVE TABLES

1. Background:

The interactive tables at EpiCrowd offered the opportunity for participants, divided into small groups, to discuss different topics of interest relating to the participatory surveillance strategy, its tools and its application in routine circumstances or during mass gatherings.

These points were presented in the form of questions to be answered by the participants, “roundtable” style. Tables were asked to report objectively, preferably on the three main topics discussed, and to provide a brief report of additional topics discussed.

To stimulate, organize and record the discussion, which were to last approximately 60–90 minutes, two individuals were assigned to each table:

• Note taker: Individual responsible for recording the most salient points discussed.

• Ideas catalyst: Individual responsible for stimulating debate and engage the participants to discuss and answer the "guiding questions."

The main points of consensus for each table were presented to the whole group. Additional points discussed are part of this report.

Given the modality of the interactive tables, "free debate" took place with rich and productive ideas generated. The heated discussions did not always objectively address the issues at hand, so in this report results are organized by theme groupings and include the content of the additional discussions that took place, albeit originally unplanned.

2. Interactive Table #1: March 25, 2015, 4:00 p.m.

In the first interactive table session, participants were divided into two rooms, each with 3–4 discussion groups. One room discussed aspects related to "participatory surveillance at mass gatherings" focusing on the app experience with "Saúde na Copa"; the other room addressed the intended “participatory surveillance to be introduced in the routine National Public Health Surveillance System." A summary of the discussions are presented below:

I. Room 1: Participatory Surveillance during Mass Gatherings:

Question 1: What expectations of surveillance services during mass gatherings could participatory surveillance meet?

It was stated that during a mass gathering, the most anticipated result of the application of participatory surveillance as a complementary tool, is to increase case-detection capacity, considering the established syndromes under surveillance.

It is also expected that participatory surveillance will promote event detection in a more timely manner compared with other traditional monitoring tools, considering that the notification is from the individual

him/herself (without intermediaries) and transmitted in real time (via wifi or 3-4G) from each user's mobile devices.

Question 2: Is there a need/interest in having data/information specific to sub-groups involved in mass gatherings?

Yes, in addition to the analysis of general population, it is necessary, depending on the character of each event, to include the flexibility to establish indicators for monitoring different strategic groups.

The consensus of the group was that "workers' health" merits special attention, directly related to mass gatherings. The group pointed out that this subgroup is frequently affected by health problems related to food-quality, unfavorable working conditions, and long working hours. These scenarios may result in acute outbreaks at any stage of the preparation and implementation of events. The occurrence of an outbreak in the workforce may also threaten the preparation and execution of the event.

Another priority group was travelers. The participatory surveillance tools should enable the identification of this public. The opportunities for the exchange of infectious agents among travelers from different epidemiological settings makes this information a strategic one for surveillance services.

The app should also be able to assess the severity of cases (hospital records of signs, symptoms, gravity and severity) and its propagation capacity (persons with a similar clinical picture).

The discussions also addressed the importance, without suggesting how, to detect, monitor and respond to events among other stakeholders (athletes, delegations and organizing committees) or vulnerable subgroups (pregnant women, children and people with special needs). The former is important due to the potential to generate a crisis, and the latter, for the priority that should be given to the health needs of these subgroups.

Question 3: What information should participants in this strategy be given back during mass gatherings?

The answer to this question was one of the most sensitive points of discussion at the interactive tables. At first, it was suggested that the user, or the general public, visualize a map or chart as a dashboard, displaying the results with the distribution of the signs/symptoms and syndromes by location. This proposal was contested by others who argued that without technical verification, events could be misinterpreted by the public, press and other segments of society to generate panic, damage or harm to the population and health services.

The debate did not reach a conclusion. However, additional suggestions of possible information users could receive, were:

• Health promotion, via push notification, appropriate to the user profile and the epidemiological context observed.

• Guidance on how the search for health services specifically related to the particular health status of the participant.

Question 4: What information would be useful to engage users in the use of participatory surveillance platforms?

The inclusion of a "game," even though not a consensus, was the one idea that stood out in the discussion of strategies for attracting and retaining (engagement) user's use of the application. Other strategies identified as possible were: the inclusion of useful information (tips); integration of useful tools in the application; to customize (settings) with issues of interest listed by the user at the time of registration.

There was a recommendation that the "game" should be developed in a manner to avoid drawing more attention than the main purpose of the application itself, the self-reporting. The ideal scenario would be that both "game and reporting" be linked, without causing information bias by influencing one another—i.e., that neither one should stimulate or hinder the objectives of the other. Another word of caution was for the possibility of the "game" encouraging participation of one age group to the detriment of others.

Question 5: What target syndromes should be included in the app during mass gatherings?

Considering the assessment of a mass gathering scenario the group suggested keeping rash, respiratory and diarrheal syndromes. The focus should still be on infectious diseases, and it was proposed that the app also include unspecified febrile syndrome.

There were discussions about the possibility of inclusion of signs and symptoms useful for the detection of syndromes related to intoxication, accidental or intentional, by chemical contaminants (humans or the environment).

There is also a need to assess the feasibility of using participatory surveillance for monitoring the events related to traumas resulting from violence. It was considered that perhaps other strategies like "active surveillance" already fulfill the role of monitoring them.

II. Room 2: Participatory Monitoring for Routine Use:

Question 1: How does gamification help to engage participants in routine surveillance?

The "games" and the awards should consider focusing on two groups: "casual users" and "expert users." They should contain few complications—if there are many obstacles, users will stop using the app. Be simple, without asking for too much data or being too complicated to understand or play.

To help with engagement, the game could offer prizes and rewards. This could occur through:

- Scoring proportional to a user's notifications frequency (and loss of points for time without report);

- Providing incentives such as virtual medals (or "badges"), health-related symbolism, as is usual in other apps;

• Awarding physical or related apps (free downloads, credits at shops, priority access to public health facilities).

Question 2: What type of games (gamification) would be most appropriate for routine use?

• Outbreak prediction projects

• School projects (e.g., a drawing competition)

• Scientific projects

It was suggested (although not very clearly in the note taker's report), that usage of games could be used as predictors of outbreaks. In this respect, it was pointed the need for more integration between the "game" and the notification. Experiences in Europe (in the note taker's report it was not clear where or when exactly) use games with this focus. It is not a competitive game. The game usage in the app can be compared with actual disease data.

The suggestion of projects in schools (e.g., a drawing competition) was linked to the discussion of the need to determine which target group we want to achieve. Using the example of children, the possibility arose of using educational games as drawing competitions. Even though the application has a broad audience, using this reasoning, other projects could target other specific age groups.

The scientific projects were included to try to assess:

(1) Whether there is scientific proof that the "games" increase the participation and adherence of users to these applications. There is a need to identify evidence that gamification expands the use of health-related applications.

(2) Which target audience could be most reached by participatory surveillance tools?

(3) With what frequency should users be permitted to notify signs and symptoms? Every 2 hours, once a day, as many times as they wish?

(4) What are the triggers to investigate a signal detected by participatory surveillance? When should health departments initiate an investigation?

Question 3: How to use participatory surveillance in routine times?

It was pointed out that the participatory surveillance tools for routine surveillance should be developed to ensure ample flexibility, to be applied to different health problems.

It was suggested it should have two modules, one for the general public and one for health professionals who are key to the notification.

The notification by health professionals (health worker, endemic diseases agents, doctors, nurses etc.) could be based on patterns of signs and symptoms, or syndromes observed, or even direct notification of health events (e.g., outbreaks or clusters of cases). Understanding that participatory surveillance should not replace traditional/official notifications systems.

Schoolchildren were considered a useful public to engage in routine participatory surveillance.

The use of "super volunteers" such as community health workers, can increase the detection capacity of participatory surveillance strategy at the community level.

Question 4: How do people participate in the strategy or how can they be enticed to become connected?

Transparency is the main element to increase compliance. Inform the public about the utility and importance of the information they are contributing. Work with issues that matter and bring benefits to the population as a whole. Issues that are of concern to the public. Define what they will get in return—this is crucial to ensure adherence. We must be able to show how we use the information that is being collected in order to stimulate reporting.

Ensure that the structure and content of the application promotes engagement of the broadest age group possible.

Another proposal was to create the possibility that the app collect notifications that refer to family and community members.

Finally, it was suggested that we broaden the scope of the events being monitored beyond infectious diseases, to subjects such as clinical conditions related to environmental risks with georeference and injuries from accidents or violence.

Question 5: What would be the possible incentives?

Give access to visualize a "map of results" (dashboard) with geolocation of people reporting, symptoms by location on the mobile devices and on the web. It is important to give feedback, show how the tool can be used to detect outbreaks and how public health will expedite control interventions. Explain how, through the self-reporting, public health can receive an early signal of outbreaks of certain diseases and how this contributes to a healthy community.

The main incentive for participation would be the stimulus to the user through the push notifications. Through these messages they could be guided to report signs and symptoms they might be experiencing or that they are aware of in the community. Advice such as "call your doctor" or "be attentive to warning signs" could be given.

Question 6: Which of the gaps (weaknesses) existing in the current surveillance system (routine), could be filled by participatory surveillance?

The group pointed out gaps in the monitoring system, but did not objectively proposed or indicate how participatory surveillance could address them.

The discussion of the current surveillance system gaps observed that most health professionals do not fully understand the purpose of disease reporting. They consider the forms too long and time-consuming to answer completely. In addition, the actions triggered by these traditional mechanisms of notification take a long time to be initiated, and feedback information is often delayed as well.

To fill these gaps the group stressed the need to introduce in the application, ways to enable the local services to closer monitor their territory, regional particularities and specific social groups within communities. This group repeated the suggestion of allowing for multipliers (“super volunteers”) to

report and encourage the reporting, including the possibility of one person reporting a situation where he/she might not be involved. The application should not be restricted to self-reporting only.

Parallel group discussions:

• Validity of data: What is the minimum amount and distribution of users to consider the results valid for a given population in the same time and place?

• Event Stages: When to start and how long to continue the use of participatory surveillance in mass gatherings: pre-event, during and after the event?

• What is the most difficult: Persuading people to join the application, or keeping them participating?

• Should a warning system be developed to remind people when they stay too long without accessing the app?

• The difficulty of the participatory surveillance strategy for routine use was pointed out, especially to capture rare or unusual events.

• There is a risk of participatory surveillance leading to increased demand for active response by local and state health authorities without these services being prepared. Users may have raised expectations.

3. Interactive Table #2: March 27, 2015, 9:00 a.m.

Question 1: In the general monitoring of the population, which subpopulation groups require special attention for participatory surveillance? What strategic approach should be implemented?

It was reiterated the need to put emphasis on workers' health, expanding the application of participatory surveillance to the detection and monitoring of different events such as exposure to chemical contaminants and adverse responses to drugs and vaccines.

For workers, a standard questionnaire could be used, without identification variables. Surveillance could include, in addition to symptoms, some risk exposures related to the type of work.

Question 2: Is it interesting to make a participatory surveillance module for health professionals/key people? Who are these people and why?

Yes, you must insert a module for health professionals. Teachers, hotel workers and community leaders were also considered key people. If the goal is to detect clusters of cases, health professionals and teachers could notify clusters, without individual identification.

Health professionals would be preferably composed of primary care professionals and emergency care (hospitals, private clinics, health centers), in order to be on the lookout and notify disease clusters in a more agile way.

Teachers and community leaders were mentioned to be key groups to provide notification of specific subpopulations such as the elderly and children. Traveler groups are difficult to be achieved in routine surveillance. Thus. one focus could be hotels.

Question 3: In addition to travelers, which the other publics should the syndromic participatory surveillance strategy cover?

• Workers directly related to travelers: service providers; suppliers; taxi drivers; food/catering services; hotel housekeeping, receptionists, etc.; tour guides; personnel at ports, airports and border crossings; security staff (police and private).

• Populations vulnerable to certain agents or conditions.

• Community health workers.

• Resident populations in the vicinity of a mass gathering.

• Pilgrims.

Parallel group discussions:

• Use the tool "verboice" for locations that do not have good internet signal;

• Keep, in the new app, the elements of Saúde na Copa that had higher membership adhesion marks: health tips, city of games, maps of pharmacies and hospitals.

• Incorporate elements in the app for monitoring adverse events and vaccine reactions—pharmacosurveillance.

• Use theme of "impact" to promote the application, for example, surveillance of influenza.

4. Online evaluation results

An online form was distributed among the participants to assess 10 points related to the performance of the event. As of 04/08/2015, 27% of the participants responded to the survey. Preliminary results were as follows:

1. How did you hear of the event?

a. Facebook: 13.79%

b. Twitter: 0.00%

c. Friends/coworkers: 79.31%

d. Boss: 6.9%

2. What motivated you to participate?

a. Opportunity to increase my network of contacts: 13.79%

b. Opportunity to learn about new health surveillance issues: 48.28%

c. My institution has asked me to participate, without I even knowing what it was: 0.00%

d. I had experience with mass gatherings: 6.90%

e. Other reasons: 6.9%

3. What part brought the most benefits to you?

a. Conferences: 41.38%

b. Panels: 20.69%

c. Interactive tables: 24.14%

d. Tech demos: 3.45%

e. Networking during the coffee breaks/lunch: 6.9%

f. Dinner get-together: 3.45%

4. What did you think of the duration of the event?

a. Too short: 10.34%

b. Too long: 0.00%

c. Ideal: 89.66%

5. And the venue?

a. Terrible: 0.00%

b. Bad: 3.45%

c. Average: 6.00%

d. Good: 41.38%

e. Excellent: 48.28%

6. How would you evaluate the networking opportunities during the EpiCrowd?

a. 0 to 5: 7.9%

b. 6 to 8: 62.07%

c. 9 to 10: 31.03%

7. Which of these themes had you heard or worked with before EpiCrowd?

a. Digital Detection of Diseases: 22.62%

b. Participatory surveillance: 23.81%

c. Mass gatherings: 25.0%

d. Computational epidemiology: 11.9%

e. Global health: 16.67%

8. And the lessons learned?

"Enjoyed all of it. I thought the discussions were fantastic and the organization spectacular."

"Will bring many new ideas."

"New technologies."

"I enjoyed the exchange of experiences on mass gatherings explained by the lecturers. As well as the methods developed for participatory surveillance."

"Sensational interaction with other countries when discussing specific topic! It was great!"

"Working with social media surveillance (crowdsourcing)."

"The organization and the technology of other countries and the ease they have to put in practice things that we know but can't implement, remaining restricted to small groups. Another thing is the institutional integration that they have. The event was good, but I suggest you start on Friday and end on Saturday night. On weekdays it has become increasingly difficult to get out of our activities."

"New frontiers of knowledge, a transnational vision of epidemiology."

"In fact, I would have liked to add a discussion that would allow integrating all the tools presented into Brazilian public health in everyday life. The experiments were important, but I believe that the next event must advance the discussions of the use of new technologies for the detection of diseases on the ground in Brazil."

"The theme DDD, Global Health and Mass Gatherings are of fundamental importance in our work environment."

"Exchange of experiences, opportunities to innovate in health surveillance—making it more effective and timely."

"Learning about experiences in other states and also the importance of information technology in health. From now on this is a fact, and states and municipalities have to buy into this need/practice/real-time surveillance, etc."

"The interactive tables succeeded in promoting a lively moment of interaction among participants, bringing together people from different areas of knowledge sharing information about a particular topic. There was also quite an interesting diversity and mixture of knowledge areas in lectures and panels."

"Panels."

"Man, what impressed me most was the interconnection of the issues addressed by the speakers and panelists. You are to be congratulated!!!"

"Great event, great speakers! Everything worked perfectly!"

"Congratulations, EpiTrack! Recife was in need of an event of this level!"

"Working with surveillance at the state-level ANVISA [FDA], I have been trying to enter the digital world, increasing surveillance sensitivity and specificity, and being more participatory—at a low cost and without relying on outside maintenance. With this event, I see a range of possibilities that can help optimize our surveillance service to make it more agile. Our experiences and those of others can help in this construction process."

"I enjoyed the panels and interactive tables."

"The method of the interactive tables was very interesting, but I think there is a need for a little more time and advance preparation by the organizers of the event. The opportunity to strengthen the network of contacts, taking advantage of all times, was one of the positive issues. The dinner was very rich and relaxed, allowing gatherings of participants. It lacked a bit of dance music, such as forró and frevo; that could have facilitated the contact between people."

"Such events should be held more often. The exchange of experiences with colleagues from other countries was phenomenal."

"There is much more beyond the SINAN (national mandatory reporting system)."

9. Would you be interested in a future event like EpiCrowd?

a. Very low interest: 0.0%

b. Low interest: 0.0%

c. Average interest: 7.69%

d. High interest: 15.38%

e. Very high interest: 76.92%

10. What were you not pleased with?

"I saw no negatives."

"Few managers of the Universal Health System (SUS) and the Academy."

"I see nothing that has not pleased me."

"Perhaps greater participation of academia."

"Longer presentation time for speakers."

"Holding the meeting during weekends. I suggest, start Thursday night or Friday. It has been increasingly difficult to get out during the week to attend such events."

“I believe that to advance in the discussions on the use of these technologies, we should involve more professionals engaged in public health surveillance, in states and municipalities, in order to enrich the debate. The event was flawless and the organizing team also.”

“I believe that the format of the event was very positive and productive. Perhaps the national experience should be further explored. More Brazilian speakers.”

“A suggestion: It would be interesting to propose a model with parallel sessions so that you can have multiple things (lectures, panels, etc.) happening simultaneously, enabling participants to choose.”