

Citizen Data-Driven Design for Pandemic Monitoring

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ABSTRACT

In a world concerned with the coronavirus pandemic, many governments do not know how to control the disease. Although there are several technologies that generate citizen data, transparency, and privacy are very important to ensure social engagement and more effectiveness in fighting the virus. This article analyzed some applications that contact tracing people or inform them about the disease. We selected the applications based on how they captured data, privacy issues, citizen participation, and the main challenges faced. Later, we created the app journey map to compare them and discovered the most used technology is Bluetooth, and the apps often have open source. However, these initiatives bring superficial insights and need to integrate with more complex data.

Keywords: Citizen Participation, COVID-19, Data-driven Design, Data Privacy, Social Innovation, Smart City.

INTRODUCTION

The coronavirus pandemic impacted the world in 2020. Consequently, many countries developed new ways to control contamination. Unlike previous pandemics, the citizens' mobility is higher, as well as the number of sensors to monitor them. The COVID-19 disease has great epidemic potential, and it is challenging to track asymptomatic people. The only tools to avoid contamination are case isolation, quarantine and contact tracing, difficult procedures to implement.

In a critical crisis context, many protocols are ignored in order to collect citizens' data. So, it is important to evaluate what is being done. This is an urgent topic, not only for the current coronavirus crisis but for a future with more monitoring technologies. The whole world shares similar concerns, and it is trying to improve public management without affecting the citizen's experience.

As many countries do not know how to track their citizens, some governments can take advantage of the crisis to increase surveillance. Many institutions launched applications, but they may not be efficient in their purpose. This article presents a comparative study between applications that intend to contain the coronavirus contamination in ten countries. It explains the importance of citizen-driven focus, understanding their behaviour, desires, and bringing them to the discussion and design participation.

1. DATA-DRIVEN DESIGN IN A CONNECTED CITY

The implementation of smart cities, where there are technologies to connect data and manage urban decisions, could be useful for epidemic control. Kitchin (2015) says that in recent years the smart cities concept has grown among industry, government, media and, academia, referring to the use of information and communication technologies (ICTs) to stimulate economic development and augment urban management.

However, according to Consoli et al. (2017), the interaction among different actors brings heterogeneous solutions. As cities have different kinds of data, the capacity to integrate them safely is essential to the smart cities interest:

Transforming our cities into the smart cities of the future encompasses incorporating technologies and key digital advances, and links them with machine-to-machine solutions and real-time data analytics. Collecting data and transforming them into tangible insights is crucial for modern innovative smart cities. (pp. 1-2)

The capacity to link various data is essential to data-driven design. This approach helps to understand some behaviours and to guide proper solutions. When cities use the citizens' data to increase their information, they expand their knowledge about them. According to Aguilera et al. (2017):

All data gathered, either automatically by the city sensors or by contributing citizens, who act as mobile sensors in their daily interactions with the city, is useful to take earlier and better decisions, providing improved services to the citizens. (p. 234)

In this way, the design modality is not only for individual subjects but also for all human activities, individual or collective. As stated by Manzini (2014), in highly connected organizations, it is necessary to operate in the design modality. "That is, design has been mainly seen in its potentiality as a problem solver. This is correct. But, in my view, design is not only that. Design can also create meanings. That is, operate as a sense maker." (p. 97).

Thus, the evolution in design research from a user-centered approach to co-design is changing the roles of the designer, the researcher, and the user. According to Sanders and Stappers (2008), the implications of this shift support a transformation toward sustainable ways of living in the future.

In a connected city, citizen data could contribute to human-centered design. According to Oliveira and Campolargo (2015), urban challenges and societal transformations contribute to a new social consciousness leading to new approaches, such as citizen-driven innovation, focused on the co-design and co-creation of city services:

Cities are smart when they take full advantage the human capital of its citizens, create innovation ecosystems where the new dynamics of wealth and jobs creation takes place and promote new forms of participatory governance. In short, when they become Human Smart Cities. (p.2336)

Besides the importance of the data, they can also reveal a lot of sensitive information about the citizen. According to Cottrill (2020), some privacy issues are critical, such as geotagged or otherwise location-enabled data, despite representing valuable inputs. Collecting location data from personal devices or aligned to identifiable individuals can be highly revealing, and someone can use them to detail traces of an individual's behaviour.

For that reason, it is important to understand the privacy and ethics concepts. For Cavoukian (2017), privacy equals control: personal control over the uses of your personally identifiable data. It is not about secrecy; it is not about having something to hide.

1.1. Privacy

With the technology progress and new ways of data capture, some countries have created and updated their laws. Some examples are the GDPR (General Data Protection Regulation) in Europe and LGPD (*Lei Geral de Proteção de Dados*) in Brazil.

Another effort to create privacy principles is the Privacy-by-design concept, characterized by proactive measures and anticipates privacy violation events. Cavoukian (2009) developed seven principles:

1. **Proactive not Reactive; Preventative not Remedial:** Anticipates and prevents privacy-invasive events before they happen. For example, a product would provide a clear commitment, with high standards of privacy and higher than the global laws.
2. **Privacy as the Default:** No action is required by the individual to protect their privacy. The purposes for which information shall be communicated, only the data strictly necessary must be collected, with non-identifiable interactions, only as long as necessary to fulfill the stated purposes, and then safely destroyed.
3. **Privacy Embedded into Design Privacy:** A systemic approach to privacy at every step in the design and operation, with detailed privacy impact and risk assessments clearly documented.
4. **Full Functionality:** There are not dichotomies between privacy and security; it is desirable to have both. It should be done in such a way that full functionality is not impaired, and to the greatest extent possible, that all requirements are optimized; all objectives must be clearly documented.
5. **End-to-End Security:** Privacy before the first element of information being collected extends security throughout the entire lifecycle. Entities must assume responsibility for the personal information security, consistent with standards that must assure the confidentiality, integrity, and availability of personal data.
6. **Visibility and Transparency:** Its component and operations remain visible and transparent to both users and providers alike. Responsibility for all privacy-related policies, the openness of information and complaint mechanisms to access the next level of appeal.
7. **Respect for User Privacy:** Empowering user-friendly options to play an active role in managing their own data may be most effective against abuses and misuses of privacy and personal data.

With technology increasing, it is crucial to embed privacy directly into the default design process. We must have privacy and innovation, embracing a positive-sum paradigm, allowing an open society.

1.2. Ethic

Likewise, the designer who works with data capture technologies must understand their decision outcomes besides to respect users' privacy. It is important to know the ethics definition; according to Barbosa and Souza (2011), ethical virtue has different interpretations because it is the result of different situations: the action in line with general laws and the actions that address the singular cases, in which the law does not apply easily, but the virtuous man is able to act according to the fair measure.

For Frascara (1997), every situation of human communication falls within the ethics field:

That is, it can be ethical or unethical but it cannot be a-ethical. The basic tenet of ethical communication lies on the recognition of the Other - the receiver of the communication - as a subject (a person) and not as an object. By recognizing the Other as a subject, the Other is recognized as an independent, thinking person, with a specific way of understanding, evaluating and integrating experiences and information. (p. 17)

Although communication can control behaviours, attitudes will not change unless there is a partnership between the message producer and the public about desirable objectives. For Frascara (1997), when attitudes do not change, the need for repressive communications, legislation, and enforcement grows. In a smart city, we should be conscious of the citizen's role as co-author; this notion seems essential from an ethical point of view. In pandemic circumstances, the co-operation and balance between all those involved are crucial.

1.3. Citizen Participation for Social Innovation

Social change happens when we not only understand citizens' data but also when they participate in the design process. The designer role is more about facilitating the conversations from various social actors than designing alone with citizens' data. Manzini (2015) defines design for social innovation as:

... is the expert design contribution to a co-design process aiming at social change. In practical terms, it is a blend of different components: original ideas and visions (from design culture), practical design tools (from different design disciplines), and creativity (which is a personal gift), within the framework of a design approach (deriving from previous reflexive design experience). (p. 63)

Citizen participation is present in a smart city environment, and this concept integrates technologies with citizen wellbeing. Mulder (2018) sees a necessary shift from city management to participatory city-making:

Such a participatory city making process envisioning liveable and sustainable urban environments goes far beyond simple, or even complex, product-service design; it has political, organizational, and even cultural implications. It interestingly offers a variety of design opportunities to engage with citizens, to empower them, and enabling a social fabric to be increasingly reflexive and responsive. (p. 179)

In the epidemic context, citizens' data are captured, and their participation helps in getting information and transforming it in public actions more efficiently. The digital application is an unfinished product; it could be improved through user interaction and participation.

2. CASE STUDY OF APPLICATIONS FOR COVID-19 CONTROL

Given the infectiousness of COVID-19 pandemic and the high transmission from presymptomatic individuals, manual control of contact tracing is infeasible. The use of a contact-tracing app that builds a memory of proximity contacts and immediately notifies positive cases would be more efficient in reducing the epidemic, in particular when combined with physical distancing. (Ferretti et al., 2020)

When the World Health Organization (WHO) decreed the pandemic, March 11, and began to discuss ways of control, some organizations created initiatives to develop technologies to monitor and, also, respect privacy. In Europe, following the GDPR, a group called Pan European Privacy-Preserving Proximity Tracing (PEPP-PT¹) created a platform for proximity tracing with a privacy-preserving approach. Google² and Apple³ also jointly created the Exposure Notifications System, which uses Bluetooth technology to identify the contacts through encrypted keys in the device operating system.

This article reports a desk-research, during June 2020, with information about applications for mapping the coronavirus epidemic in several countries. We choose ten examples (Figure 1) from different continents that track the population or alert about possible contamination.

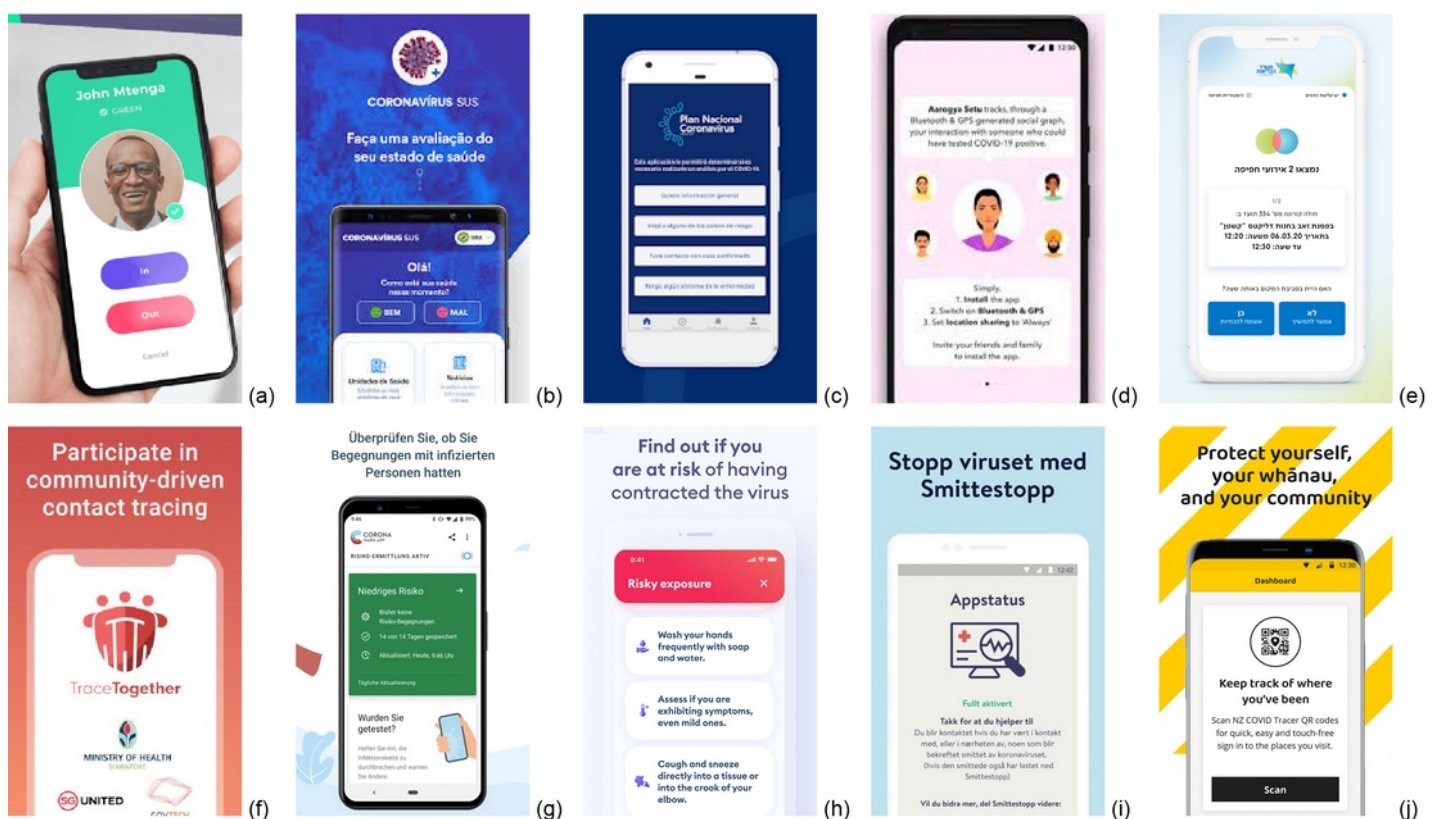


Figure 1. Applications screen: (a) South Africa - Covi-ID, (b) Brazil - Coronavirus SUS, (c) Uruguay - Coronavirus UY, (d) India - Aarogya Setu Mobile App, (e) Israel - HaMagen, (f) Singapore - TraceTogether, (g) Germany - Covid-Warn-App, (h) Italy - Immuni, (i) Norway - Smittestopp (j) New Zealand - NZ Covid Tracer app.

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We chose nationwide applications, so examples from the USA were not selected because its initiatives came from each state. We researched official communication sources; therefore, applications from China and South Korea were also not selected because they did not

provide information in English, which made analysis impossible. These sources were considered because the goal was to analyze public communication.

We analyzed how the population is using the apps during the research period, although it is not a strict experience, as the situation quickly changes and some updates could not be covered. We searched for the apps on the government official websites, in the Apple and Google stores of each country, and on the WHO website.

Table 1. The data investigated in the study.

• Application operation description;	• Who developed it;
• Source data location;	• Source data from COVID-19;
• Device permissions;	• How long personal data is stored;
• If the user can delete your data;	• Mention of citizen participation;
• The privacy policy and explanation beyond the terms of privacy;	• Transparency with the data and what will be done with it;
• Open source code;	• Date of the first confirmed case;
• Date of app release;	• Confirmed cases on the research day;
• Rating in the application stores;	• Number of reviews.

From these collected data (Table 1), we created the applications journey (Table 2) to compare the different stages. The development stage details the involved agencies, citizen participation, and if it is open-source. The usage stage highlights how the app works, the technology to capture location, and health information. Finally, the post-use stage shows when the data is deleted; and the pain points of each initiative.

We observed that there are many technologies for capturing the location: two applications use QR code, two GPS, and six Bluetooth. Of these, three use Exposure Notifications technology, five said they developed with citizen participation, and seven are open source. In Brazil's case, the application already existed before the pandemic; it was updated but still has no contact tracing.

3.RESULTS AND DISCUSSION

After comparing the applications, it is possible to make some relationships, find patterns, and highlight challenges. In the next sections, we divided the insights into four major subjects: technology and data, privacy and transparency, citizen participation and, risks and challenges.

3.1. Technology and Data

















































After Apple and Google announced a partnership to develop Exposure Notification technology, some countries have released their application or updated to this new technology. Despite this, Bluetooth is still an inefficient technology, as it cannot identify different floors, walls separating people, the type of establishment, or whether it is a closed or open place, for example.

For public services to work efficiently, many systems capture multiple data sources. As Cottrill (2020) summarizes, we can separate them by:



- **Public Data** held by governmental organizations, such as health information provided by the Ministry of Health in the case of Singapore, India, Israel, Uruguay,

and Brazil. In New Zealand, Germany, Italy, Norway, and South Africa, the user self-notifies with test information.

Table 2. Selected applications journey

Country	Deployment		App	Geolocation	Using	Stored data time	Pain Point
	Built	Open Source			How it works		
South Africa			 Covi-ID		The citizen generates an ID with QR code that has health status. Trader download an app that scans it and identifies an infected person	As long as it takes	Organizations checking who is free can be invasive and embarrassing.
Brazil			 Coronavirus SUS		The application does not track, it has information about the disease, symptoms check, nearby hospitals, among others	Not specified	The content is a pocket website version, with no need to download.
Uruguay	 		 Coronavirus UY		With the Exposure Notifications technology, the application traces and notify contacts if someone has reported infection	15 days	With a few cases, the government needs to convince the population of the app utility.
India	 		 Aarogya Setu Mobile App		The application detects other devices with Bluetooth, exchange digital signature with information about time, location, and duration.	Negative: 30 days Positive: 60 days	Data shared with many agencies, making privacy difficult.
Israel	 		 HaMagen		Crossing the smartphone GPS history with the geographic data patient history	Location: 7 years Other data: 30 days	Population confidence in government and data usage.
Singapore	 		 TraceTogether		The device stores the data. It will only be shared with the government if the user tests positive	25 days	Bluetooth may not be accurate.
Germany	  		 Covid-Warn-App		Exposure Notification technology creates a temporary encrypted ID. Citizens can voluntarily report they positively tested, share their temporary key, and the app notifies other contacted devices	Negative: 14 days Positive: 21 days	Many companies involved, making privacy difficult.
Italy			 Immuni		Exposure Notification technology, a health professional inserts the COVID-19 test voluntarily	Until December 31, 2020	Released after the epidemic peak, citizens may not engage.
Norway	 		 Smittestopp	 	If diagnoses COVID-19, the app identifies other users who have had contact. Everyone will receive an SMS with recommendations	30 days	They discontinued the app because of personal data usage.
New Zealand			 NZ Covid Tracer app		The user creates a digital diary of the visited places by scanning the official QR codes at the entrances to business premises, other organizations and public buildings.	31 days	Population and organizations engagement.

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Application development participation:  Governance  Citizen Participation  Research Center

Technologies for capture location data:  Bluetooth  GPS  QR code

- **Private Data** acquired by a private firm, such as mobile phone usage, data from RFID tags and QR code, as in New Zealand and South Africa.

- **Data Exhaust** often useful when combined with other data sources. Such data may include internet search histories, location traces from mobile phones, or interaction records from Bluetooth Exposure Notification technology, used by Germany, Italy, and Uruguay. Or, yet, to track cellular networks, as in Brazil and Israel.
- **Unstructured Community Data** captured as part of social interactions, such as the research groups Ghost Data and Visua in Italy, which identified several violations through Instagram photos with tagging in lockdown regions. They offered this technology to the government, but it was not used in the app.
- **Self-Quantification Data** revealed by individuals through self-monitoring or tracking. Singapore is testing to replace the Trace Together app for a device the user would carry with them. (Balakrishnan, 2020)

Some countries analyze the contagion by self-assessment, which is a reasonable alternative when there are not enough tests to verify the entire population. In the case of India, they categorize the users into four risk status, assessed by themselves or by official tests: for example, the orange risk reported the symptoms and the red one tested positive.

3.2. Privacy and Transparency

Applications can be sorted into two groups: centralized, those with data processing on cloud servers; and decentralized, with processing within the devices. In the centralized model, health authorities have higher control, while the decentralized offers more security for citizens' privacy. Apple and Google support the decentralized model. In Germany, they emphasize the project's philosophy is the decentralization of technology; the population has more confidence, and the government does not concentrate on data storage.

We analyzed the ten applications from the seven privacy principles from Cavoukian (2009):

- **Proactive not Reactive; Preventative not Remedial:** nine applications already have clear information about the privacy policy and the data destination on the official website. In Brazil, the privacy policy was only found in the application, upon download.
- **Privacy as the Default:** eight applications explain how long the data will be stored, and that it will be automatically deleted after a certain time, without requiring any user action. The only ones that do not specify are South Africa and Brazil. In Israel, even those location data considered irrelevant will be stored for seven years.
- **Privacy Embedded into Design Privacy:** seven applications make open-source code available and invite people to participate and inspect the code security. The only ones that do not mention being open source are New Zealand, Norway, and South Africa.
- **Full Functionality:** Exposure Notification technology creates a temporary identity and does not require the user to be logged in; you can use the application without providing personal data. The apps with this technology are from Germany, Italy, and Uruguay.
- **End-to-End Security:** Some applications have partnerships with several companies and government agencies; sometimes from different countries, so with different

legislation. Thus, they need to be responsible for data in all processes, which can be more difficult, as in the cases of India, Israel, Germany, and South Africa.

- **Visibility and Transparency:** Even declaring that a lot of user information is not required, some applications ask for permission to access many device features, such as Singapore, Israel, and South Africa.
- **Respect for User Privacy:** Not all applications clearly explain how the user can request their data, as in Israel, Italy, and Brazil.

Society has been discussing privacy, and many applications already have concerns about these issues. As the legislation is different in each country, the approach is more or less restricted.

3.3. Citizen Participation

In general, the applications' promotional material invites the population to help fight the coronavirus. Being everyone's problem, they claim that citizen participation will bring more data and better results. We highlight some projects that report citizen participation, at the beginning and during the use of the app, from:

- **South Africa:** They developed the application to include people without technology; thus, to use the QR code, users without a cell phone can print the code and take it in their pocket;
- **Uruguay:** The government credits the Uruguayan technicians' efforts and the participatory attitude of all citizens for the country position with cutting-edge technology and to implement, verify and certify the app;
- **India:** There is a reward program for those who find a bug in the app and help to improve security;
- **Singapore:** The government's digital services agency proposes to design for citizens, bringing solutions after listening to them. They constantly test and iterate to understand citizens' pains and to build better products;
- **Germany:** The government website invites all citizens to participate in application development. They credit the global open source community as a partner;
- **Norway:** Initially they tested in three cities before expanding to the entire country. The idea was to find out if it would have adherence and improve the product, but it was not completed;
- **New Zealand:** The app only works with active citizen participation: the user should scan manually the QR code, and the company voluntarily prints the poster.

Despite the official sites report of citizen participation, as described above, we did not find an explanation for this occurrence. Thus, it is challenging to explore what is efficient and engaging. Anyway, we noticed higher cooperation in the code development of the applications.

We analyzed the development applications time, as some took longer since the first case of COVID-19 or since WHO declared a pandemic (Figure 2). Thus, the released time influenced

the application's performance. Also, we highlighted the announcement of the Exposure Notification technology, which some countries used later.

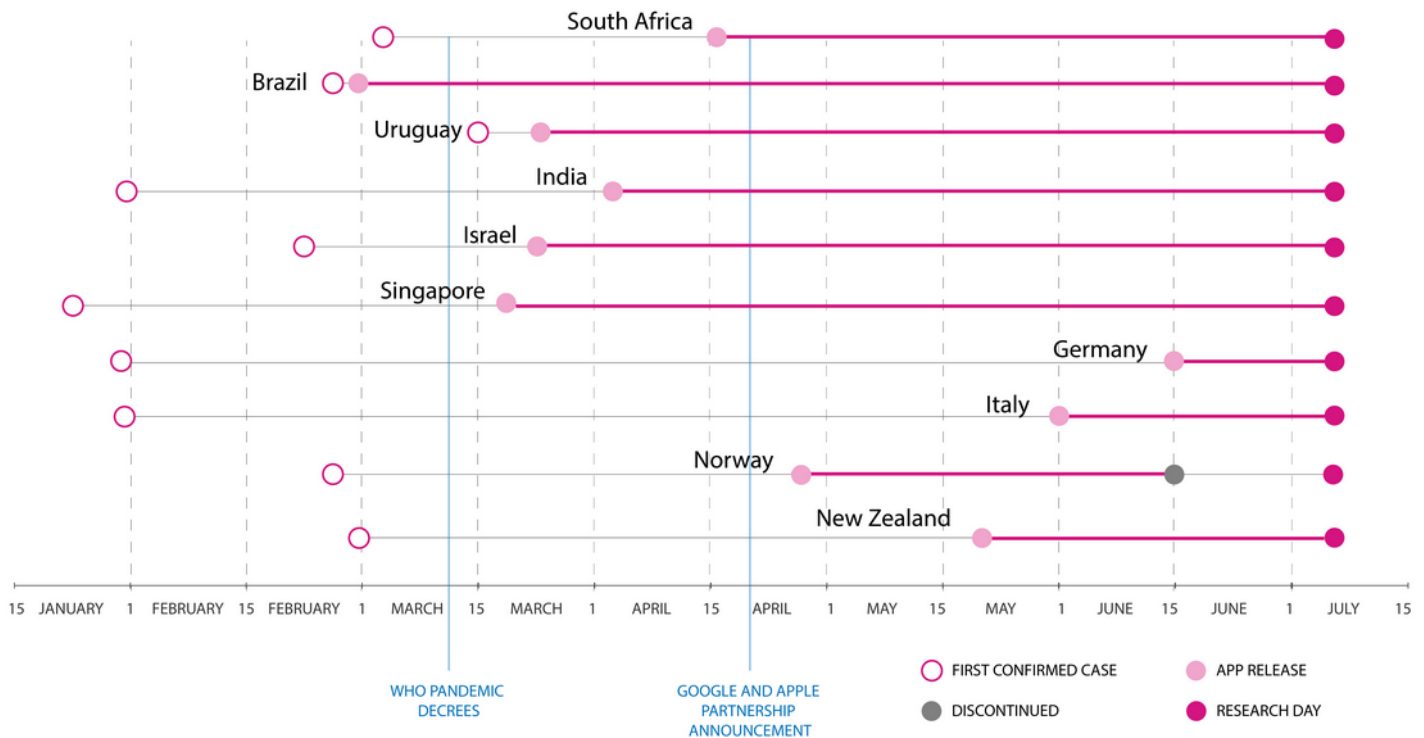


Figure 2. Development applications timeline.

The apps' effectiveness is yet unknown, as they have been running for a short time and there are other factors involved. In the case of Italy, for example, the application was launched after the country's epidemic peak; therefore, perhaps citizens are no longer so engaged. In Uruguay, as there are few cases, the communication emphasizes that, even so, it is important for the population to use the app.

Figure 3 shows the relationship between the average application rating in Apple and Google stores by the number of confirmed cases on the research day (5/7/2020), the number of user reviews per day (since some applications have been available for longer), and if the code is open.

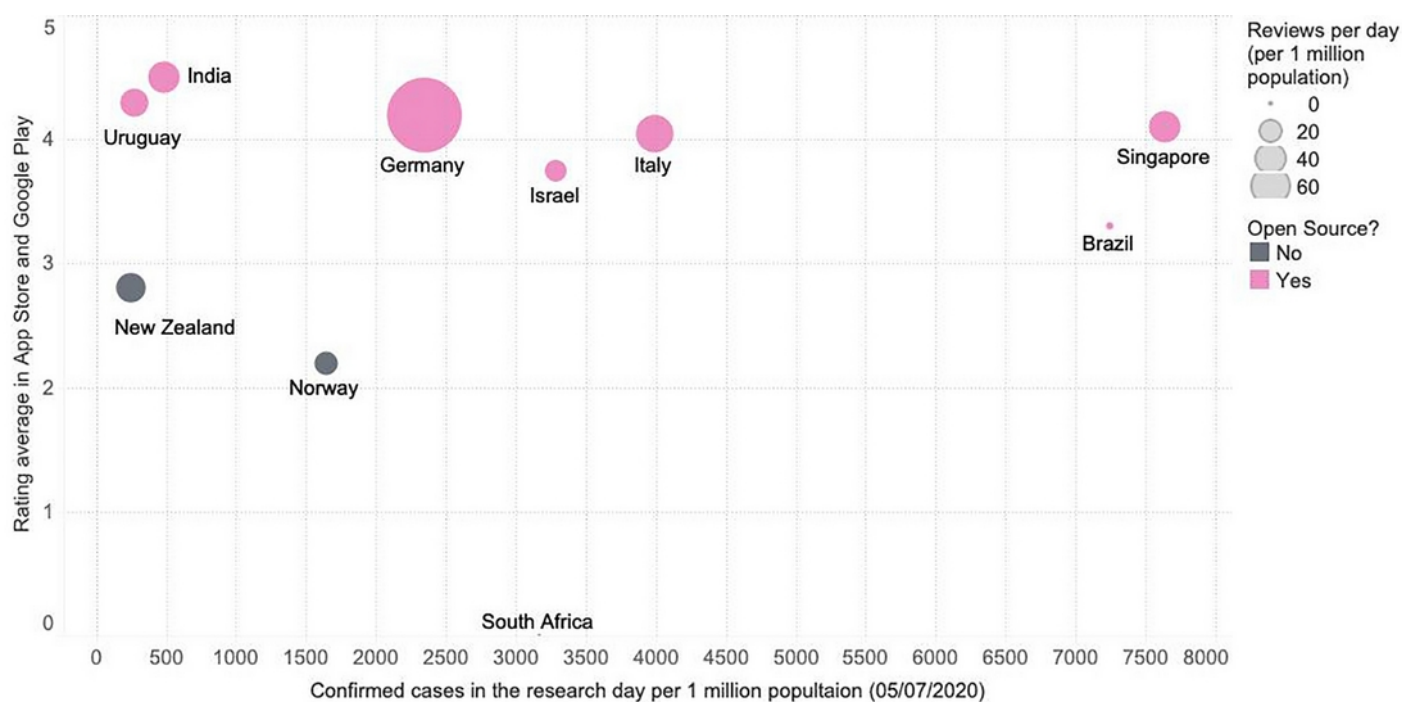


Figure 3. Chart with applications rating per confirmed cases.

The best rating apps in app stores is open source. However, it is not possible to make a direct relationship between the evaluation of the application with combating new confirmed cases, as there are many factors involved.

3.4. Risks and challenges

The challenge is not only to know where a person went but also the type of place. Marino et al. (2020) say that a multidisciplinary approach is necessary, as the complex simplification of a heterogeneous territory ignores essential urban elements to understand higher or lower propensities to contagion.

Another issue of ethics and privacy is the South Africa case, where business employers are responsible for scanning QR codes and checking who is allowed to enter. This dynamic can be very invasive and embarrassing, even more, if the country has a racial segregation history.

In Brazil, the lack of data transparency and application utility are challenges, since the app's content was available in other media. This lack of clear utility added to the privacy issues also bring doubt on the relevance of these products. In the Norway case, the application has already been discontinued; the Norwegian Data Protection Authority notified it about data use. They believe that COVID-19's low cases do not justify the privacy violation. Figure 3. Chart with applications rating per confirmed cases.

Another challenge is transparency and trust from the population to enable their participation. According to Kitchin et al. (2015), when people play a central role in data gathering, it is assumed an objectivity method to produce transparent, impartial, and bias-free data. Data can be measured and recorded in numerous ways, and each can be interpreted differently.

For Carugati (2020), a possible solution for fairer technologies is to create a citizens' council that regulates the algorithms. Resolving social problems requires that many voices be heard, the original lesson of democracy, meaning better citizen governance.

The partnership of different authorities is important for transdisciplinarity in innovation. According to Mulder (2018), when a core group is shaped from a bottom-up initiative, it has strategic support included and remains representative of the community in general. Co-creative partners participate in multiple initiatives, which allow them to act as connectors and cross-different levels in the ecosystem, strengthening the social fabric.

This partnership is important not only to ensure the project continuity but also because transdisciplinarity brings different visions to innovation. For Manzini (2015), design for social innovation helps the protagonists to achieve results they would not be able to achieve alone. These social forms "appear with widely differing characters and purposes, but they have one clear characteristic in common: their existence requires the active, collaborative participation of all interested parties." (p.77)

4. CONCLUSIONS

The study results may contribute to designers by giving information on privacy issues in handling citizens' data, an overview of available technologies, the challenges faced, and how to communicate clearly with the population. As presented previously, this research was a temporal cut. The study had a time limitation, so it was not possible to evaluate the product full cycle, such as it was elaborated and concluded.

Therefore, it would be relevant to analyze the applications during and after the pandemic to understand if their use will continue, if the data will be erased or manipulated for other purposes, and if this type of application was relevant in this context. For future work, the research could investigate apps in languages other than English and federal apps. Some cities' populations could be larger than in some countries.

The information available in the official media is limited and partial, so the researcher should investigate with transparency and without biases. Being a time frame, technologies can change, applications can be updated, or others can arise, but the concepts analyzed in this research are broader. They can be discussed and applied in other initiatives, not only in the pandemic context.

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ENDNOTES

¹ <https://www.pepp-pt.org/>

² <https://www.google.com/covid19/exposurenotifications/>

³ <https://www.apple.com/covid19/contacttracing>

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