

## FORUM'S FLASH RECOMMENDATIONS ON COVID-19 EMERGENCY

Affecting populations around the globe, the COVID-19 emergency poses several challenges for those who are charged with taking decisions for their local communities. These decisions, made during a time of crisis and with a sense of extreme urgency, require an unprecedented effort by the local population, who must renounce part of their individual liberty in return for the broader public health, solidarity and protection of those who are most vulnerable.

Whilst acting in a situation of extreme uncertainty, and with pressures to react swiftly to preserve the health of their citizens, responsible local authorities must also preserve fundamental human rights and principles. This is a key element of *responsible* governance, and is also a key component of *effective* governance since transparency, and guarantees of fundamental human rights and principles, are essential to reinforce trust between citizens and local government. Close cooperation between regional authorities and citizens, both in their role as part of the community and as (potential) experts in their own right, is essential for tackling the COVID-19 emergency, both in health and socio-economic terms, and trust plays a major role. The mobilization of an empowered civil society is an important factor both during and in the recovery stage of the crisis. For example, citizens may actively contribute beyond being compliant with governance decisions by collaborating to find novel strategies for mitigating the spread of the contagion or through co-creating new approaches to speed-up the recovery stage post-crisis.

Particularly in times of emergency, the Forum is convinced that a Responsible Research and Innovation compass can effectively guide responsible governance decisions and, through transparency, trust building and the harnessing of co-creation potential, can contribute to the effectiveness of governance decisions.

With these flash recommendations, the Forum aims to provide the Lombardy Region with a list of suggestions and reflections on the governance of key themes - in line with Forum's role and competences - which regional decision-makers may have to deal with both in these current days and in the recovery phase.

Along this document, the Forum will focus on:

- **Measures: 1) Clearly articulated, transparent and science-based; 2) Socio-culturally situated**
- **Communication**
- **Data**
- **Technologies for containing and detecting contagions: 1) AI and tracking apps; 2) Tests**
- **Innovation at times of COVID-19: 1) Citizen-led actions; 2) Volunteer engagement; 3) Collaborative innovation; 4) Social innovation and entrepreneurship**

## **MEASURES**

The current situation requires difficult choices, impacting severely the habits and life of all citizens. Therefore, to design a trustworthy approach for the various difficult decisions made, the Forum recommends that any action is inspired by two fundamental principles: it is always clearly articulated, transparent and science-based (1), and it is appropriate to the social and cultural context in which it needs to be implemented (2). These two points are elaborated below.

### **1. Clearly articulated, transparent and science-based**

The current situation is very new for the scientific community, tasked to understand the virus and its effects and much is still subject to scientific debate. Because of the naturally high global interest, usual scientific discourse and disagreements are placed in the spotlight in real-time and broadcast around the globe, leading to conflicting opinions and scientific evidence - the very nature of scientific research. Despite this fluid situation in the scientific community, the most basic principles and the consequent measures necessary to contain viral outbreaks are largely known and already tested in other similar epidemic circumstances (i.e. SARS epidemic). These measures include accurate and effective hand-washing and social distancing.

In this situation, it is crucial that all the measures and procedures adopted by the authorities for both containing and detecting contagions are transparently linked to specific and clear-articulated scientific evidences. Understanding that knowledge of COVID-19 will evolve and change in the short-term, *clarity* and *transparency* on the evidence-based decision is key for building trust. Access to such evidences should be provided in an accessible, coherent and transparent way (See also the sections "**Communication**" and "**Data**").

### **2. Socio-culturally situated**

Singapore and Korea have been extremely aggressive in containing SARS-CoV2 using many different measures, from the screening of incoming visitors in airports, extensive testing methods and contact tracing through compulsory apps. In China, a wide usage of surveilling AI-based technologies and drones have been deployed. The combination of such measures can be very effective but is also very intrusive (See also the section "**Technologies for containing and detecting contagions**"). This kind of strategy has been accepted by those local populations who are used to high-degrees of tech-surveillance but will not be as acceptable in other countries, for example the majority of European countries. Thus, the implementation and application of similar strategies in the Lombardy Region should take into account the different socio-cultural contexts so as to plan a proportionate approach in line with local values, which is sensitive to the public acceptability of tech-surveillance. Furthermore, a clear and open communication on the actions and the objectives of such approach should accompany the whole strategy and its implementation (See also the section "**Communication**").

## **COMMUNICATION**

When facing the global pandemic of COVID-19, transparent and timely information is crucial to strengthen trust between local institutions and citizens, to favor adherence of inhabitants to preventive measures and procedures, and to limit the diffusion of unverified (and so potentially inefficient or risky) tests, tracing apps or drugs.

- One of the pillars of preparedness and effective response during situations of emergency is good communication, which has to be carefully planned, in terms of messages to be delivered, with clearly defined channels to be used and presented with the most appropriate style.

- Even in extraordinary situations, communication should be designed to enhance solidarity and social connections in order to collectively tackle the crisis, instead of individual blaming of the very few who are disrespectful of the measures - such amplification of a few cases may undermine solidarity and thus risk perturbing the positive collective response of society. The highlighting of positive examples, such as bottom-up solutions achieved through spontaneous collaborative initiatives can be a powerful tool to reinforce the sense of cohesion and the active role that society can play (See also the section on “**Innovation at times of COVID-19**”).
- Communication must be supported and complemented by clearly-sourced data. Most of all, the figures of a pandemic of such proportions and impact needs also to be clearly articulated and incorporated into infographics with clear explanations. Informative material from an institutional source would be important in framing the crisis and helping to explain the rationale behind the measures for isolation and tracing being implemented. The quality and reliability of data to be diffused needs to be carefully conveyed (See also the section “**Data**”).
- At the same time, communication on the evolution of the outbreak should not only revolve around data on deaths and dramatic human experiences. Such a focus may overshadow other data sets which may provide a more balanced view of the evolving situation. Moreover, the limits of the data must be conveyed, with details of both the gathering of data and in its interpretation. All data are mediated by pre-existing health and social situations, available technology, and local practices. Thus, communication using data should be structured to represent both the necessity of understanding the pandemic in a data-driven way, whilst also remaining conscious of what the data does not (and perhaps cannot) tell us. Furthermore, communication regarding updates on the outbreak evolution that is sensitive of citizens’ concerns, fears and personal dramatic experiences should be prioritized and promoted by institutions towards the media.
- The spread of COVID-19 has seen an explosion of fake news hyping cures and trials of “miracle molecules” or suggesting obscure plots. Such fake news spreads rapidly and can have significant negative effects. An institutional web resource collecting fake news and debunking, supported by a strong social media presence, may be very helpful in containing the so-called “infodemic”. At the same time, it is important that institutional websites are continuously updated with reliable information and resources presented in a clear way.
- Efforts could be focused on addressing citizens’ questions regarding new and fast-changing regulations that are sometimes difficult to understand while having a strong impact on their way of life. Local policymakers could decide to directly address people’s questions (through mediated channels). As a further step, Q&A sessions could be organized and collected in institutional websites to answer to target-audience specific questions, such as children, teachers, parents, as well as industrial actors, senior citizens, etc.

## **DATA**

While collection criteria, quality control and interpretation of data related to the epidemic is under continuous scrutiny, whilst not always be reliable (See also the section “**Measures**”), such scrutiny can only happen if all data (clinical, epidemiological, research) and the conditions of their collection are widely available and accessible. Open data would help to ramp up and speed up the understanding of the disease, of the characterization of this virus, of the diffusion of the outbreak, of the efficacy of the measures undertaken and, above all, of the effectiveness of the general management of the emergency. Scientific, epidemiological, clinical data (of course preserving

privacy, in line with GDPR) and all other forms of data that can be helpful for understanding the phenomenon shall be open and easily accessible both to researchers and to the public. Such data availability is also essential for public scrutiny and to enhance bottom-up and collaborative innovation (See also the section on “**Innovation at times of COVID-19**”).

- Governmental authorities should encourage anyone who collects or generates data about this pandemic (clinical, epidemiological) and the SARS-CoV-2 virus (clinical and research), to make the data readily available. At the same time, since standards about data structures and metadata are still missing, contributions to their development should be actively pursued to be able to capitalize on global efforts, exchange usable data and implement quality control.
- Open data should be accessible in an easy to use way (i.e. not released as PDF documents, or with proprietary file formats which cannot be read through an algorithm). This is the only way to facilitate and harness community and crowd-sourced analyses, and to gain new insights. In fact, anyone might develop a game-changing idea if all the data was continually accessible and open to further contributions. Many competitive community challenges<sup>1</sup> have been organized around the world on this topic, and they all rely on the availability of open data.
- A common platform where anonymized data on infections, patients and trends are made open and available (as done in the past with the data on the spending and emissions of Expo2015) would be a valuable resource to add transparency and evidence concerning the measures implemented (See also the section “**Communication**”).

## **TECHNOLOGIES FOR CONTAINING AND DETECTING CONTAGIONS**

Technological solutions have been increasingly called upon as key elements for the mitigation and prevention of the effects of the COVID-19 crisis. In this document the Forum would like to focus on the governance of technologies for monitoring and testing. In this realm, the pendulum relentlessly swings from over-expectations to fears, from sound evidences of efficacy and uncertain results. We believe that clear illustration of threats and opportunities as well as trade-offs is crucial for designing and implementing technologies that are both useful and socially acceptable. Furthermore, communication on social impact of key technologies should be a priority in managing the transition and phasing-out period (See also the section “**Communication**”). Specifically, we list in the following some of the key issues that should be taken into account.

### **1. Artificial Intelligence and tracking apps**

Many European national governments, including Italy, are considering the possibility to use tracking apps for proximity tracing as a way to ease current restrictions for citizens’ movements. While these apps have been considered as an opportunity, they have raised many concerns about their implication of digital surveillance on citizens’ rights and social life. Information about the exact functioning of the app is still scattered, but in order for this app - to be developed at national level but to be tested or rapidly applied to the Lombardy Region, which is very likely for the major impact of the outbreak in this territory - to be responsibly designed and implemented, several conditions should be met:

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<sup>1</sup> Such as: Virtual Covid biohackathon <https://github.com/virtual-biohackathons/covid-19-bh20/wiki>, or public data beacons by the Global Alliance for Genomics Health <https://mailchi.mp/ga4gh.org/june-2019-chair-letter-2678014?e=60b040d359> or #EUvsVirus Challenge: <https://euvsvirus.org/>

- Design choices in the app have to be carefully evaluated in how they meet data protection requirements and privacy rights. Although there are good arguments for the need of reducing the scope of the right to privacy in an emergency situation (where other liberties and rights are also affected), since these apps will be used for several months and since several design options can be chosen, it is important that the choice takes into account citizens' rights as much as possible. This means that:
  - Data collection should be proportionate and reduced to the minimum necessary. At the end of the emergency period- clearly defined and stated-, data collected should be deleted.
  - Data access should be reduced to as few actors as possible, clearly defining and communicating which public authority has access to it and who has access to identifiable data.
  - The different technologies and data streams exploited by a tracing app should be carefully evaluated as GPS based apps give one kind of information (are you approaching an high risk area; are you violating your quarantine) while bluetooth apps collect and deliver information on proximity of infected or potentially infected individuals.
- Oversight and auditing should be conducted by independent parties including both experts and civil society organizations. Such oversight is necessary in order to evaluate design choices, data use and access, app effectiveness and necessity, the role of big tech corporations, data retention and use of data (once an app has access to a mobile device it may also access data related to web browsing through cookies, shopping habits, frequency of calls with other individuals, opening vast possibilities for profiling habits and behaviors beyond the scope of health safety).
- Transparency. The objective of its deployment must be clearly communicated to citizens if the app is used for law enforcement, if its usage is voluntary or mandatory; what kind of data will use, store, process and for what duration. Furthermore, the role of technology in the broader strategy should be clearly articulated: if tracking contacts and contagions without pairing with more effort in testing is neither effective nor useful, the use of these apps is not well justified. If apps are introduced as experiments then this should also be made clear (See also the section "**Communication**").

## 2. Tests

The increase in testing capacity is clearly an important issue, to enable full implementation of WHO guidelines. In terms of participation and research community involvement, the PCR-based test (mouth swab) relies on a technology which is widely available in common research labs. The involvement of the wide scientific community would allow increasing the scale of PCR-based testing, but current regulations are quite stringent to ensure diagnostic-grade certification of laboratory results. The Forum would therefore support the following principles:

- Relaxing temporarily clinical diagnostics regulations and requirements - only for emergency purposes, with clear statements on the duration of the relaxation, to allow the participation in this effort from numerous research labs who have volunteered their instruments and personnel to increase COVID-19 testing capacity in safe environments.
- Sharing a common protocol for the safe handling of patient materials and the distribution of non-infectious material to the labs who volunteer to run the tests, thus allowing wider involvement of research labs.

In the current situation, as a response to the COVID-19 crisis, all over Europe we have observed the emergence of thousands of private and civil-society initiatives offering help and support to those affected by the current crisis, creatively overcoming urgent issues in medical equipment and tools shortage, providing innovative and low-cost solutions.

### **1. Citizen-led actions**

Citizen science initiatives are supporting the identification of sociological, economic and psychological impacts of lockdown measures on citizens, providing valuable information that could be used to foresee new emerging issues. Nonetheless, most of these citizen-led initiatives remain excluded from institutionalized calls for action (i.e. financial support through ad-hoc calls) that are mostly addressed to universities and other types of research institutions.

The societal response to the current crisis also represents a great opportunity to tackle key issues that governing bodies are struggling to address while at the same time being fully focused on managing the health crisis, for example, the impact on the populations most vulnerable to the coronavirus and economic hardships. Engaged community members are spontaneously setting up initiatives to support segments of population at risk. Endorsing and supporting such initiatives would lead to positive empowerment effects in the long term.

### **2. Volunteer engagement**

Research on resilience has shown that citizens behave in a highly supportive and cooperative manner during times of severe crisis and exceptional situations. Instances of anti-social behavior are rather uncommon and, if they occur at all, tend to be over-emphasized by media coverage. Experience shows that most public administrations struggle with meaningfully involving volunteers coming from outside established organizations such as the Red Cross. Very often this leads to frustrations on the side of the citizens who rightly expect a certain degree of appreciation. At the same time, valuable resources that can help to tackle the crisis, and its socio-economic effects, remain under-utilized.

Drawing on experiences from other crisis situations (such as the European refugee crisis 2015), the following lessons can be drawn:

- There is not just one type of volunteer. Instead, volunteers are heterogeneous with regards to their skills and resources. Administrations should therefore quickly register the different skills and resources the different types of volunteers are willing to offer.
- It is essential that administrations are open towards all different kinds of voluntary engagement. Even citizens without any institutional backing can effectively provide support to administrations and other citizens. Only tasks with (health) risks should be reserved for trained professionals. In any case, no offers to help should be rejected categorically, even if this might entail some additional effort initially.
- Administrations need strong relationships with civil society organizations (CSOs). The high number and diversity of offers to help can quickly overwhelm professional crisis managers. Thus, it is important for the administrations to collaborate with CSOs to support them in the processes of recruitment, training and fielding of the volunteers.

### **3. Collaborative innovation**

All over Europe, as well as in Lombardy, there have been amazing examples of collaboration among FabLabs/makerspaces and local hospitals to quickly respond to the shortage of unexpected big amount of medical equipment and tools, producing them thanks to additive manufacturing technology. Most of these initiatives have been led by communities spontaneously self-organizing to combine their strengths to find out rapid, and very often low-cost, solutions.

Regional governments may play a twofold role regarding collaborative innovation:

- It could support or provide a central organization, for instance through the regional Open Innovation Platform, to manage resources and communication of hospital needs. This would accelerate and scale-up these scattered examples, and this effort could be beneficial also for the recovery phase and in the longer term.
- The regional government could also highlight some major systematic challenges and call for funds and collaborative solutions that are open to all kind of initiatives. These challenges may also target the recovery phase, for example, calling for solutions to improve home care services and related technologies.

#### **4. Social innovation and entrepreneurship**

Social innovation in the Lombardy region is also represented by more structured third sector organizations, in particular social cooperatives and social enterprises. These constitute an important pillar of the regional welfare system and will play a crucial role in offering new and practical solution to emerging social needs related to COVID-19 disruption. Third sector organizations, such as social enterprises and social cooperatives, are experiencing very difficult times: half of them are engaged on the front lines of the emergency with exponentially increasing risks and costs. The other half (e.g. kindergartens, education, transportation services) has completely stopped operating, with activities and revenues drastically reduced. Preliminary estimates suggest that a remarkable number of social organizations are at risk of disappearing, or will not be able to resume normal operations, beyond the summer. This will result in severe problems for the regional welfare system and will deprive Lombardy citizens of an important source of responses to their needs. Regional authorities should anticipate and consider special support measures for social organizations, both through the emergency and in the post-emergency phase when a profound disruption of social innovation models is likely to take place. Such measures should include capacity building, financial support, technology support and knowledge transfer.