

Pan-European Response to the ImpactS of COVID-19 and future Pandemics and Epidemics

# Online workshop: PERISCOPE Workshop on Holistic Policy Guidance for Pandemic Response for Policymakers

Deliverable 8.1





# **PERISCOPE**

# Pan-European Response to the ImpactS of COVID-19 and future Pandemics and Epidemics

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### PERISCOPE Workshop on Holistic Policy Guidance for Pandemic Response for Policymakers

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#### **EXECUTIVE SUMMARY**

The PERISCOPE Workshop on Holistic Policy Guidance for Pandemic Response for Policymakers aimed at providing space for interaction between policymakers and PERISCOPE researchers, to co-design the content of future guidance documents to be drafted in the context of WP8, and to be later integrated in the PERSEUS-COVE platform. A virtual workshop was organised on 24 June 2021, attracting a total of 41 participants. Roughly half of them were external guests. The workshop was divided in two group discussions on five topics, namely:

- (i) Resilience and Sustainability;
- (ii) Multi-level governance;
- (iii) E-heath and Data;
- (iv) Mis/disinformation; and
- (v) Inequalities.

The focus group discussion and the plenary session were facilitated using an online interactive whiteboard tool – MIRO (https://miro.com). Overall, the workshop achieved its expected aims and enabled participants to express their views and shared their experience. PERISCOPE researchers could collect precious information from the workshop discussions, which will contribute to the drafting of a policy guidance document and also to the development of training packages by researchers involved in PERISCOPE WP11. This report summarises the discussions by the participants.



#### 1. INTRODUCTION

The workshop was held from 14:00 to 17:00 CET on 24th June 2021.

#### 1.1 Aim

The workshop provided a virtual space for PERISCOPE researchers to meet and interact with policymakers at all levels of government. The workshop was designed for researchers to listen to and learn from policymakers who have encountered various challenges in their daily work during the COVID-19 pandemic. Policymakers may need guidance in a certain area and the PERISCOPE research team aimed to identify existing problems and deficiencies in the current governance system. Eventually, we will digest the information collected in the workshop and prepare a policy guidance document, as well as provide ideas to training packages designed by the PERISCOPE partners involved in PERISCOPE WP11.

#### 1.2 Agenda

The agenda of the workshop is provided below:

14:00-14:10 Welcome and Introduction of PERISCOPE - Andrea Renda

14:10-14:30 Overview of the Discussion Topics – Andrea Renda

14:30-15:15 Group Discussion I

15:15-15:30 Break

15:30-16.15 Group Discussion II

16:15-17:00 Plenary Session: Report of Discussions

After a short introduction to PERISCOPE, an overview of the topics to be discussed was provided by PERISCOPE Co-coordinator and Strategic Director Andrea Renda (CEPS). The slides are available as annex 1 to this report.

After the introduction, participants were split into 5 groups, each dedicated to a specific topic. In each group, we had a moderator, a MIRO manager and a notetaker to facilitate the discussion. The moderators were experienced researchers who had prepared some materials to guide the discussion. MIRO managers wrote down notes on the MIRO boards and summarised main ideas or conclusions on the boards for a short presentation in the plenary session (see Annex 2 for the final MIRO boards). After the first group discussion session and a 15-minute break, the participants were assigned to

another group and discussed another topic. Finally, all participants joined the plenary session, which provided time for participants to respond to the ideas generated by other groups.

The five topics were selected based on the results of a pre-workshop survey, namely:

- Resilience and Sustainability
- Multi-level Governance
- E-health, Data and the Digital Technology
- Information and Communication
- Inequalities

#### 1.3 Invitation process

In line with the rationale of the workshop, the target audience of the workshop was the future beneficiaries of the holistic policy guidance that will be developed based on the information collected during the event. To ensure that the team could create an atmosphere in which participants can freely share their experiences and challenges encountered during the pandemic, the organisers aimed to collect around 30 participants for the workshop.

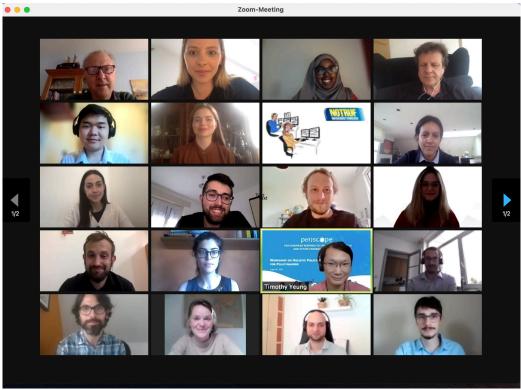
The invitation process started in mid-March 2021. The team collected a list of participants from a number of sources. First, partners participating in WP8 were asked to mobilise their network and reach out to potential participants. WP8 partners directly reached out to these participants and remained in touch with them throughout the preparation process. Approximately 30 participants were invited this way. CEPS furthermore reached out personally to PERISCOPE sister projects and those academics, policymakers and other officials who signed support letters of PERISCOPE at the proposal stage. Approximately 50 invitations were sent this way. With the lead of CEPS, a high number of cold emails were sent to national policymakers, national COVID-19 Task Forces, better regulation experts and Commission officials. Another 50 people have been invited this way.

Despite showing some degree of flexibility regarding the date of the workshop, many invitees were unavailable. The main reason for this was that those officials and policymakers which were directly involved in national and European pandemic response were still overwhelmed with work and had little time to share their experiences. There were also several last-minute cancellations due to unforeseen circumstances. Ultimately,

25 external participants attended the workshop including sister projects, academics, and national policymakers.

Two screenshots of the participants are attached below:





#### 1.4 Selection of Topics

For the selection of the workshop's topics, the team conducted a pre-workshop survey in which 12 respondents participated. Respondents could rank topics from 'not important at all' to 'very important' and suggest additional topics to be discussed. The most popular topics included inequalities, resilience and sustainability, communication and cooperation between different levels of governments as well as vaccine policies and mental health. The workshop covers all of these topics, although there was no dedicated group for vaccine policies and mental health. Instead, these topics were used as case studies under different topics.

#### 1.5 Allocation of Responsibilities

Andrea Renda, the Co-ordinator and the Strategic Director of PERISCOPE, began the workshop with a short introduction of PERISCOPE and then gave an overview of the five selected topics to be discussed.

Each breakout session consisted of five groups. Each group was led by a moderator who guided the discussion, a Miro manager who put down notes on a Miro board, and a notetaker who kept a more detailed summary of the discussion. The duties were allocated among PERSICOPE WP8 partners fairly and equally. Moderators were responsible for presenting ideas of the group discussions in the plenary session.

#### 2. Summaries of the Discussion

#### 2.1 Resilience and Sustainability

**Moderators and Notetakers:** Laure Guillevic (FEAM), Marco Di Donato (EUREGHA) and Hieu Nguyen (CEPS)

Resilience is defined as the capacity of a system to regenerate itself after a particular shock. Sustainability is defined as capacity to meet the needs of the current generations without compromising the ability of future generations to meet their needs.

#### 2.1.1 Definitions of Resilience and Sustainability

Members of the focus group discussed the definition of sustainability and challenges encountered in the incorporation of the notion of sustainability in policymaking. One participant pointed out the difficulty of the concept of sustainability: it requires the current generation to be able to predict and investigate the future to decide what that next generation would do now. Another participant proposed more flexibility for the definition of sustainability: The notion of sustainability should differ based on the level of projects or governance: national, regional, or local. Moreover, there are differences in countries and population groups in the perception of resilience and sustainability. These differences arise amongst others through the availability in data, ways through which different ethnic groups can voice their decisions and how the government listens to them.

The preliminary definition of resilience given was the ability for a political entity to absorb and overcome shocks. This view point was challenged by a participant that proposed to take a broader perspective on the issue and to embrace resilience in terms of international peace and security. In that sense, resilience, in addition to its capacity to withstand shocks, is also key build up political structures with mechanisms that can recognise and trigger potential reaction to security threat due to unexpected pandemic. The example of the Ebola pandemic was brought up to illustrate how a pandemic can threaten international peace and security and maintaining security cannot be achieved without finding a consensus between partners about public health and enforceable measures. Resilience can also be seen as a concept useful in times of emergencies and life-threatening events.

#### 2.1.2 Resilience and Sustainability in policymaking during the COVID-19 pandemic

There was a consensus in the focus group that during the pandemic, the approach to crisis management did not leave much room for incorporating sustainability. The main focus of policymakers was to cope with crisis management such vaccine development and distribution, applying lockdown measures, providing hospitals with the best possible tools to deal with the high number of patient admission. As a matter of fact, there has been a sudden shift in policy activities towards this necessity to face more urgent challenges which resulted in leaving aside ongoing health preventive measures. A priority shift has been clearly observed. However, there is optimism for the presence of more sustainable policy approaches in the future.

Members of this focus group agreed that fast decision-making during the pandemic came with various problems: decisions had to be taken without any impact assessment or evaluations. Consequently, in the long term, these policies could create more harm than benefit. For example, there might be currently too much focus on COVID-19-related policies and less attention to other threats or illnesses that are harmful as well, leading to long-term consequences.

For the future, participants proposed a guidebook, or rules on how to prepare for emergency measures to preserve sustainability. Regarding the political system itself, participants pointed out that during this pandemic, more democratic countries are often expected to fail at providing a fast, strong, and effective response when facing a crisis such as COVID-19. In democracies, public health policies are based on democratic processes and these might take longer and not always provide the best possible health protection for the overall population. This kind of inequality limits their ability to be featured in policy decisions and they may suffer most. There was also an agreement that the EU has not responded effectively because of the complex political structure that may include several drawbacks in the policymaking process. There needs to be a mechanism to recognise, detect and deal with epidemics in terms of planning, policy enacting, and the implementation of initiatives. In addition, as a result of years of public spending cut, government and administration do not have enough resources to deal with unexpected events.

Lastly, the pandemic showed the side effects of digital transition, which has pointed to the importance of cybersecurity. According to the participants, ensuring the security of digital health platforms and tools is a crucial factor to build citizens' trust in the institutions and the public health sector.

#### 2.1.3 How to ensure Resilience and Sustainability in a Post Pandemic World

Regarding the future, participants agreed that ways should be found to incorporate sustainability and resilience into the policy making processes.

There is a need to consider sustainability in a broader spectrum to cover different sectors and areas. An important element of a sustainable action is its ability to perpetuate in time and to continue when the project ends. Establishing regular action plans participates in an anticipatory work that could become central in case of disturbance as activities would continue following provisions enforced by the action plan. Participants identify three different pathways on how to concretely implement sustainable policies: First, policymakers should see beyond their national borders, align regional and national frameworks, and look for other policy examples outside their local ones. Second, policymakers should consider sustainability as a process, which takes on incremental updates and milestones. Moreover, informal networks should be maintained with influencers, institutions and possible champions. Third, policymakers should establish a culture of collaborations so that a consensus-based approach can be reached. In practical terms, implementing sustainable policies includes recognizing different types of measures and trying out new policies in various areas (one of the examples can be the establishment of small innovation hubs or policy sandboxing to implement new ideas).

Regarding resilience, lessons should be learned from this crisis: Who is the holder of the learning process and fruits after the pandemic? There is also a need for other types of expertise for further sustainability and resilience relating to different disciplines and professions.

There were also more practical solutions proposed by the participants. One noted, for example, the need for embedding resilience in the quantitative and qualitative impact assessment in a country during the pandemic to ensure the sustainability and resilience of policy responses. Another participant highlighted the work of inter-ministries as an exemplary working approach that seems to be worth expanding. Moreover, the

institutional anchoring between changing governments is very important to ensure unity of vision and intention in the medium- and long-term.

#### 2.2 Multi-level Governance

**Moderators and Notetakers:** Elin Pöllänen (Karolinska Institutet), Walter Osika (Karolinska Institutet), Agnes Sipiczki (CEPS), Carolin Formella (CEPS)

Political decisions can be taken vertically (local, regional, national/federal, European levels) and horizontally (communities, non-governmental actors, associations, companies, patient groups). Multi-level governance describes the way power and responsibilities spread vertically between many levels of authorities and horizontally across multiple actors. Moreover, especially during the COVID-19 crisis, discussions evolved around centralizing or decentralizing power. The concept of a European Health Union is a proposal put forward by the EU Commission to strengthen the EU capacity to respond to health emergencies. This includes the One Health Approach: recognizing the interconnectedness of human, animal, plant and environmental health and using collaborative mechanism/tools to bring together medical, veterinary and environmental expertise to better tackle pandemics.

# 2.2.1 Do you think the current multi-level government system performed well during the COVID-19 pandemic?

Members from the focus group came from a variety of countries and could therefore share different experiences. Regarding helpful and successful practices, the most frequent answers included close vertical cooperation between different levels of government, namely local, regional and national, as well as horizontal between different fields of government (such as for example Social and Health). Some participants noted positively that, overall, there has been more communication between authorities than ever before. Moreover, participants from some countries reported an evolution of cooperation between local, regional and national governments during different phases of the pandemic. At the beginning of the pandemic, most measures were taken at the local or regional government level and came with tensions not only between authorities but also between the public and governments. This materialised for example in the UK with Manchester trying to disagree with national measures or with a lack of understanding of new measures among citizens. At a later stage, federal governments developed a national roadmap and tensions calmed down. At the same time, participants pointed out that the European Union only has weak competence in the area of health. Members of the focus group from the UK also highlighted close cooperation between policymakers and scientists. Practically, this included regular consultations to exchange about upcoming measures. There was, however, a consensus among participants that there has been a politization of science and scientists in some countries in Europe, and that some of the Nordic countries and United Kingdom can be taken as positive examples of how to shape a good relationship between politics and science. This was also discussed in regards to the relation and communication between the civil service and policymakers, where participants highlighted the need for more research.

Members of the focus group also identified areas of improvement. Some participants shared their view that the COVID-19 pandemic revealed gaps in a system of governance, which ventures on quick wins and thinks from one election to the next. At the same time, it raised the hope that the pandemic forces and enables more long-term discussions. Members of the focus groups also stated that one of the main challenges in decisionmaking, mainly at the beginning of the pandemic, were taking ad-hoc decisions based on little to no data, evidence and analogies. One concrete example from the beginning of the pandemic is the integration of datasets from different regions - design and collection of data sets differed immensely not only between countries but even between regions. The members of the focus group however also discussed the well-preparedness of East Asian countries and the hesitance of Western countries to take lessons from Asian countries, but also ignoring good examples from nearby countries such as Norway. The uncertainty regarding how to best manage the pandemic, and the time-sensitive urgency of the situation, might have led to decreased levels of compassion and empathy during decision-making, with impaired capacities of perspective taking and creative, innovative solutions.

#### 2.2.2 What are challenges for the future?

One main challenge for policymakers seems to be communication and engagement with citizens. Although they reported that cooperation and communication between different authorities improved throughout the pandemic, they pointed out that there is still much potential to increase trust and solidarity among citizens, and invite citizens to engage more in the decisions. One concrete example, as already mentioned, was the scientific communication and engagement by policymakers that has the power to facilitate or decrease levels of trust. Moreover, also increased transparency was identified as one facilitator of trust, especially regarding what kind of data and principles in case of lack of data were used. For example, participants reported that, in the case of Sweden, there was lack of an "arena" (beyond the press conferences held by the public health agency), where different viewpoints on the management of the pandemic could be discussed there was no balanced way to handle scientific critique of e.g., the national public health agency policies (that deviated very much from neighbouring countries/EU), leading to a

polarised discussion, mostly via social media, and paving the way for trolling and conspiracy-theory spread. Complementary, further discussions on this topic took place in the focus group on disinformation.

#### 2.2.3 What are opportunities for the future?

One opportunity for the future identified by the members of the focus group is the increased attention of societies for public health. However, one question arising is how this will materialise. There might not only be a change in the public's perception of personal responsibility but an increased appetite for regulation. One of the concrete examples mentioned by the members of the focus groups is wearing masks. It is unclear if people will tend to wear masks more in the future or if there will be rules in place to ensure the wearing of masks. Another topic mentioned in this context is to upstream the momentum of increased awareness and transform the society and how we govern the world in terms of our relation and approach to wildlife and animals. Now more than ever societies see the urgency to minimise the risk of another pandemic and adapt a holistic approach such as the One Health approach, that in itself seems to need an update regarding e.g., transparency about specific agendas of One Health stakeholders, and regarding the lack of an international One Health legal framework including accountability measures.

#### 2.3 E-health, Data and the Digital Technology

Moderators and Notetakers: Michele Calabrò (EPF), Elizabeth Storer (LSE), Chiara Del Giovane (CEPS)

Participants of this focus group on E-Health, Data and Digital Technology agreed that COVID-19 accelerated the use of health data in numerous ways. Participants agreed that even if the starting point was a situation in which digitalisation was already widespread, the pandemic pushed to go further in the direction of digitalisation. Data has been crucial for decision making during the pandemic, several dashboards have been produced to record the evolution of the pandemic in terms of new infections, death, capacity of hospitals, vaccines distribution, to then make policy decisions. Furthermore, data is important to ensure continuity in patients care or to allocate patients or manage hospitals.

A participant made clear that national experiences varied according to different contexts and in particular national success stories are linked with the amount of national investment done in IT services before the emergency period. Indeed, if infrastructure for data collection and data protection are already well-developed and fully integrated in the system before an emergency period, then data management during an extraordinary period would be much easier.

Another participant affirmed that the daily work of a decision maker must be assisted by information and data, which should be available easily and rapidly, and decision makers should have the possibility to compare different datasets. In particular, the need of having comparable datasets emerged during the situation of emergency brought by COVID-19. Importantly, participants also highlighted the needs for having reliable data and for addressing possible conflicting interpretation of data, to make sure that the citizens have trust of the policy decisions taken on the basis of the data collected.

Indeed, several participants identified trust in data as an important challenge to tackle. Data could be biased in several ways, so it is fundamental to ensure the quality of data. Even before data collection, there should be some discussions on the possible role and use of data, considering that the use of wrong data would lead to wrong decisions.

Several participants also agreed that both qualitative and quantitative data should be considered before proposing a policy decision, while sometimes decision makers overrely on quantitative data.

Besides the use of high-quality data, another challenge is the correct and uniform interpretation of data among different authorities. Indeed, different decision makers might derive different conclusions from the same data. It is then important not only to share data, but also to share the decisions and the strategies elaborated after the analysis of the data. Communication of data and its interpretation is important to avoid confusion and misunderstandings.

Another important challenge identified by the participants concerns data sharing, data protection and data storage. The participants called for a better leadership of the EU in this aspect. Also, the issue was perceived by the participants as particularly complex also because different types of data require different levels of protection, therefore standardisation and better guidance at European level would help.

Furthermore, one participant argued that it is important to clearly identify the obstacles for access to data. It should be made clear what the legal obstacles are.

When the participants were asked to propose some improvements for better preparedness to future emergency situations, some main points emerged from the discussion: to have a better data infrastructure, to have standards set by the EU on dealing with sensitive data, to empower citizens to use their rights as owners of personal data, to better develop skills and competences needed to understand and analyse data.

#### 2.4 Mis/Disinformation

**Moderators and Notetakers:** Marco Brambilla (POLIMI), Mathyas Guidici (POLIMI), Francesco Pierri (POLIMI) and Rosanna Fanni (CEPS)

The first session focused on discussing if disinformation has been a problem regarding pandemic control. A participant agreed that their administration faced problems in supplying correct information and thus misinformation has been given a fertile ground. As information dissemination was not well planned, local guidance had not been well-received by citizens. In the UK, vaccine hesitancy was relatively low. One participant suggested that media had played a strong role in giving public officials, ministers and experts airtime. In the Netherlands, mistrust in public media had become more common. Many fringe (anti-vaccination) groups have been very visible online, promoted anti-lockdown ideas, and organised hugging parties. There is always a tension between the freedom of speech and misinformation. Who is capable to judge what is misinformation? In the UK, the public health committee spoke to the public every day. It may lead to fatigue but has contributed to trust building, even if the government has no specific strategy combating misinformation.

A participant questioned the possibility of regulating misinformation outside the European Union, and suggested a global effort of managing misinformation seems necessary.

However, there is a risk of over-emphasizing misinformation on the social media. People receiving or spreading misinformation online were actually talking to themselves only.

The second session further investigated the reasons behind the rise of misinformation during the pandemic. One identified that the remote and rural areas tended to be more affected, suggesting that education and demographics as two main reasons behind the spread of misinformation. As people stayed at home for most of the time, they obtained information through Internet where COVID-19 deniers were better at communicating their messages to a broad audience. On the other hand, administrations' actions might lack transparency and thus fuelled the spread of misinformation. Contradicting messages made people confused and gave credibility to misinformation.

#### 2.5 Inequalities

**Moderators and Notetakers:** Rosa Castro (FEAM), Fatima Awil (MHE-SME) and Dennis Vetter (GUF)

#### 2.5.1 The pandemic affected the population unevenly

The pandemic has affected communities (such as ethnic and geographic) differently, and in many cases the pandemic served as a catalyst to amplify inequalities that in turn made managing the already difficult situation more complex. The central problem to coming up with good mitigation plans was that the pandemic is an unprecedented exception, where no best practices from previous experiences exist. Estimating long-term implications of measures is still difficult due to the very limited data available.

During group discussion, current data were highlighted which suggests that in the general population women, students and the elderly are especially affected, and it was discovered that certain communities were affected significantly more than others.

**Women** are more exposed to the pandemic, as they are more likely to work in people facing (and therefore high-risk) occupations, i.e. nurses, teachers, cashiers. Working at home while schools were closed also increased the need of taking care of children. Mitigation measures were also often targeted at out-dated perceptions of families with one breadwinner and one caretaker which then in turn highly put single parents at further disadvantages.

Another highly impacted group is **students**. Their quality of life decreased substantially. As without school and extracurricular activities, their contact with other people and ability for social interaction decreased drastically. Existing inequalities in access to education were magnified given the existing differences in income and background. In Norway special effort was put into keeping schools - especially elementary schools - accessible for students that live in small flats, students without access to computers, and for students with parents in essential occupations (i.e. medical professionals). This mixture likely helped reduce stigma of going to school during the pandemic and it was observed that the areas that managed to keep schools accessible had better academic results and mental health among students. The **elderly** also face various problems as they have less resources or access to tools for advocating on their behalf.

Due to the limited availability of data policy making was relying on anecdotal evidence. This in turn makes policies rely on existing **connections between groups and the local**  government and pre-existing trust and relationships have become invaluable. A reflection from the group included the need for analysing existing structures of consultations to engage the most marginalised populations, often referred to 'hard-toreach' communities. Such modes of communication were deemed essential, not just in times of crises, but as part of structures for continuous feedback in policy processes. Such systems of consultation should take into account the realities for specific groups e.g. limited digital access etc. In the UK context, it was highlighted that the typical topdown approach was ineffective for engaging key communities. Connecting with influential community members (or champions), through dedicated programmes, were indicated as an effective way to not only disseminate information such as COVID-19 measures, but also receive feedback from particular groups, with the champions building the bridge and trust between the two. For example, the connection between faith communities and the government worked really well, however, these communities have only limited ethnic and geographical reach. In cases where engagement with local government did prove to be a good platform, local community champions were supported. This co-design of policies with different groups helped tailor the policies to their needs during the pandemic.

An additional point to consider is to what extent **government surveillance is required to give a voice to certain groups and communities**. As an example, in the UK data on ethnic groups and where they live is available which in turn makes it possible to design policies that target i.e. certain Bangladeshi groups with a certain economic standing. In many other countries this is not the case. Information on ethnic groups might be valuable as i.e. in the beginning of the pandemic certain minority areas in Norway were hit especially hard. While their socio-economic situation (no working from home, small apartments) were used initially to justify the more severe infection, increasingly available data showed that even after correction for these factors some minority communities were more affected.

#### 2.5.2 Inequalities and recovery plans

**Social and economic recovery plans** are on their way. An important challenge is to plan while the pandemic is still ongoing. Among these measures, a difficult system to design is a furlough system that aims at maintaining income for a large number of people to avoid them falling into poverty. Another challenge is that the pandemic leads to a much higher demand for social welfare.

Another key for recovery lies in **schools**. Areas with open schools have much better academic results and mental health among students. Additional measures in the form of financial support for students at home and better access to catch-up tutoring and summer schools are also aimed at mitigating the pandemic's influence on academic results.

#### 2.5.3 Needs of policymakers

While a big obstacle in the crisis is the silo-thinking in government agencies, to a certain extent the pandemic has enabled some cross-sectorial work with different ministries involved. It is likely that exchanges of best practices across Member States will also prove beneficial in such situations. To facilitate fluent exchanges, it should be ensured that the required structures exist before a crisis.

Quick actions by policymakers were enabled by three key things:

- 1. Data that could be analysed and transformed into action
- 2. Relationships between the government, communities, and other stakeholders to co-create policies in the potential absence of data
- 3. Processes and governance mechanisms that allow quick responses to unprecedented emergencies with only limited information available

Going forward, there is a **need for more available information**, as health is affected by many different determinants, and it is difficult to gauge the effects of different variables. With more data / information available this evidence can be used to convince policymakers and move policies forward. Necessary information comes from collecting more data or from a better and deeper involvement of groups that proved to be vulnerable during this pandemic and a better representation of different groups in decision making. Beyond that it is also important to reflect on the fact that inequalities already preceded the pandemic (e.g. housing, income, ...) and the essential role of schools for not only for education, but also mental health and social activities of students as well as reducing strain on parents.

Finally, **reflection on lessons learned and collection of best practices** can help being more prepared for comparable future extreme situations.

#### 3. Notes

The team would like to thank Niamh Aspell, Louise Barr, Diana Beljaars, Coen Bergman, Diotima Bertel, Stefano Bolzoni, Roberto Cibin, Robert Dobric, Anna Estopa, Andreea Furtuna, Katja Glavič, Åse Marit Hovden, Sonja Linskeseder, David Mcdaid, Jacqueline McDevitt, Horand Meier, Benedikt Montag, Stephan Rut, Anni Skipstein, Theoni Spathi, Siegfried Weinert and Jelka Zaletel for their participation. We are also grateful to all PERISCOPE participants who were not involved in WP8, including Tim Allen, Jelena Angelis, Pascal Garel and Lucia Gonzalez. Names are ordered alphabetically.

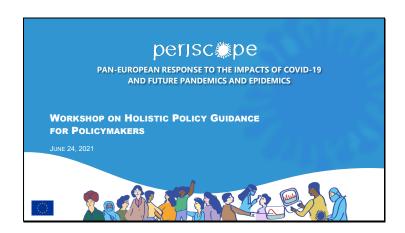
Personnel involved in the preparation of the workshop:

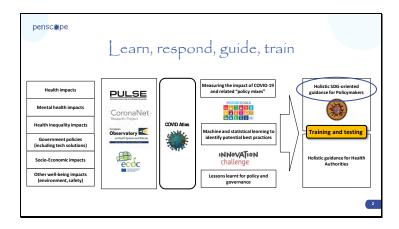
Chiara Del Giovane, Rosanna Fanni, Carolin Formella, Hieu Nguyen, Andrea Renda, Agnes Sipiczki, and Timothy Yu-Cheong Yeung (CEPS); Michele Calabro (EPF); Marco Di Donato (EUREGHA); Rosa Castro and Laure Guillevic (FEAM); Dennis Vetter (GUF); Elin Pöllänen and Walter Osika (KI); Elizabeth Storer (LSE); Fatima Awil and Laura Machetti (MHE-SME); Marco Brambilla, Mathyas Giudici and Francesco Pierri (POLIMI).

#### 4. Annex

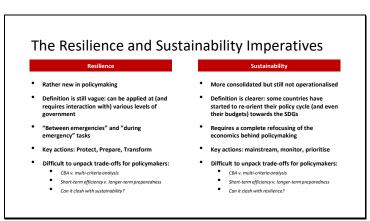
#### 4.1 Slides

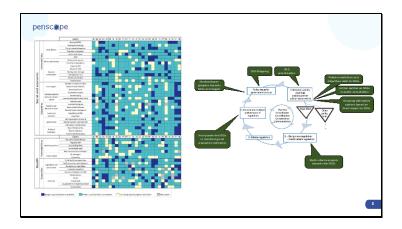
Slides of Andrea Renda's presentation are attached below.











#### Multi-level governance

- Who should do what?
- Do policymakers have a smooth communication with upper and lower levels of government?
- How effectively were decisions coordinated across levels of government? And between governments and the EU/international level?
- Links with other topics:
  - Central coordination + local empowerment = resilience?
  - Information and communication
  - Inequalities: local areas/groups



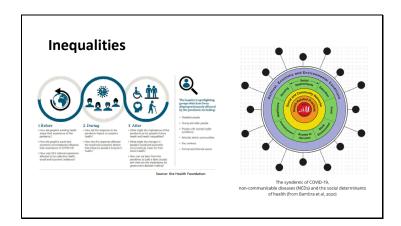
#### (Dis)Information and communication

- How to avoid the spread of disinformation in times of emergency?
- How to communicate science to citizens, for example in the context of vaccines?
- What organisational structures and technical tools coud be deployed to contain the spread of disinformation?
- Does disinformation depend on the level of trust in institutions and their communication?
- Did policymakers face new challenges during the pandemic, which would benefit from guidance in the future?

#### Digital health and data

- How to leverage the potential of digital health in times of emergency?
   We look for good national practices on the handling of health data, their sharing and overall merging of public and private data for preparedness and response
- What governance arrangements for digital health?
  - Centralised v. distributed v. decentralised data storage and processing
  - Privacy-preserving practices and user control over data
- What are the key issues on which we could provide guidance to policymakers?
  - Interoperability, Trustworthiness, Privacy and IP protection
  - Leveraging non-traditional data sources (e.g. social networks, telecom companies, search queries, mobility data, etc.)

     Untapping the potential of data collaboratives for local decision-making and preparedness



#### **Breakout Group Discussion** perisc@pe

- Each of you has been assigned to a specific group
- Moderators will reflect the content of the discussion by using a Miro board
- Moderators will then report the main outcome of the discussion in the plenary session: everyone is welcome to respond and give additional feedback

#### Reminder

- We will not record the meeting today.
- · We will not specify your names in any subsequent documents.
- Encourage interaction between Health Authorities and Researchers

Breakout Session

#### 4.2 MIRO Boards

Link to the MIRO boards: <u>PERISCOPE WP8 Policymakers Workshop</u>, <u>Online Whiteboard for Visual Collaboration (miro.com)</u>

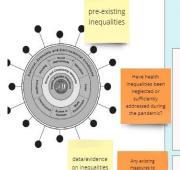
#### **Inequalities**

During the pandemic, we have often heard that "we are all in this together". However, there is some evidence that the pandemic has impacted the population unevenly, Initing harder the most marginalised in society, include those with lower income, occupation or education levels. For instance, workers with low occupation status may be more vulnerable to COVID-19 because they cannot afford buying sufficient PPE while others require on-site working, Groups with low income and poor housing conditions may live in overcrowded spaces where the infection risk is high. Furthermore, some groups may have experienced limited access to health care, which can in turn lead to further health inequalities.

Moderators: Fatima Awil (MHE), Dennis Vetter (GUP), Rosa Castro (FEAM)

Round 1

#### Questions



Do you think the pandemic affected the population unevenly?

Do your recovery plans address economic and social inequalities?

What are the needs of policymakers to support in addressing inequalities e.g. guidance/training





#### Presentation/ Summary

- how to go from collecting data & gauging effects to policy action? Some countries systematically collecting data had an advantage in designing responses that included the voice of vulnerable groups (e.g. in the UK, the collection of data on race/ethnicity before the pandemic, enabled fast responses through involvement of community champions in the responses. Collecting data is just the beginning. There is a need for good analysis/understanding of the effects of many variables on inequalities and then the transformation of this into policies.
- -many policy responses such as school closures led to complex effects. Mitigating inequalities requires to look at broad effects for affected groups (youth/children, families, vulnerable groups). It also requires designing solutions that support the groups in need without leading to stigmatisation. Other measures such as social security/income measures require fine-tuning (how to address the needs of different family structures, etc.)
- -important to define which groups are vulnerable? youth/children were vulnerable to many impacts, including on mental health. The elderly/frail were particularly affected and might not be so active on advocating for their interests
- -social and economic recovery plans are being designed while the crisis is still unfolding. Rapid learning is key but it is challenging to reflect on lessons learned and design future-proof plans while dealing with an emergency
- -what is needed? (1) reflections on lessons learned (breaking silos & more collaboration); (2) better (and more diverse) representation in decision making for instance in terms of gender; (3) attention to affected vulnerable groups

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#### E-Health, Data, Digital aspects

Technology has occupied a very important role during the pandemic, from contact-tracing apps to using Al to read chest scans. Patients' experience could also be enhanced through telemedicine. On the other hand, the need of data protection and lack of data sharing scheme hold back the exploitation of the benefits of

Moderators: Michele Calabro (EPF), Liz Storer (LSE), Chiara del Giovane (CEPS)

#### Questions

Pre-pandemic digital infrastructure

E-health and digital communication during COVID-19

Building infrastructure post-pandemic

data crucial for decision making during the pandemic (mass screening/ national arrivals) experiences differed across contexts depending on per-existing digital infrastructure digital data important to ensure continuity in patient care/ policy development digitisation accelerated during the pandemic e.g. production of dashboards

# CHALLENGES

Obsolete nature of pre-existing health databases
Novel demands, e.g. number of tests and instaneity of feedback Novel demands for access across different levels of

government/ health services/ citizens How to manage huge quantities of data? Are health professionals ready to deal with digitisation? How to manage **conflicting interpretations of** 

#### data? Reliability of data? Sources of data?

Data protection/ storage laws restrict use of data, but may uphold the rights of citizens = different conversations/ concerns between citizens and

organisations Decentralisation of data: federal verus national government levels ls data linked to controlling populations?

#### Round 2

- > B2G and G2G Exchanges achieving results linked to context, network and capacity to make data shareable.

  Negotiate the right conditions.
- > At the beginning of the crisis more willingness to share data, but lack of infrastructure > Technology to handle data might not take much time, but
- finding the right people to work with it's harder = social aspect of digitalisation of care. Even digitalisation is really driven by individual people with different ways to handle digitalisation, but it raises questions on interoperability. > WE are missing the baseline and real assessment of the
  - actual issues related with data.

    > Issues with large volume of data available but not standardised and therefore not really usable.
- > Issues with underrepresentation of some groups in large datasets, potentially biasing the results coming up from such data analysis.
- > Qualitative and quantitative data interaction is complex and continuous challenge. However, taking both levels in consideration is essential. Only numbers analysis can lead to misinterpretation.
- > Analysing data collected at different moments of the nic is extremely challenging (different focus, different ways to collect data)
- > One one hand, having the same pacing of information and data analysis we had for COVID-19 on other diseases/health issues, would be positive. However, the data not always led to the right political decisions - interpretation.
- > Data to improve care and improve decisions --> However,
- Data to improve care and improve decisions -> However, wrong data can also lead to wrong
  It is important to identify what the data will be used for when starting collection.

  Citizens should have a stronger voice on health data. If we accept the approach that we own our data

  More collaboration between data stakehodlers is crucial

  We will have to look at how the data helped us to manage the pandance or circinization and focus. the pandemic -- prioritization and focus.

#### Presentation/ Summary

- 1) Variation across contexts, but COVID-19 has accelerated the use of health data in numerous ways. Data should be easily and rapidly accessible. comparable to other databases for quick and clear decision making (from day-to-day to policies)
- 2) Experiences differenced according to national investments in IT services and their integration with government departments and health services 3) Given the importance of data in directing policy, how can we assure its reliability? How can citizens trust data and decisions based on it? 4) Match quantitative and qualitative data, also considering potential biases, is fundamental.
- 5) Data quality is essential: wrong, biased data can lead to wrong decisions for policy making and care. Furthermore, the purpose of data collection should be very clear from the beginning, also for the sake of healthcare professionals.
- 6) Data Interpretation, use and communication: even with high quality, clear datasets, there might be issues related to how data is interpreted different experts, different approaches), use and communication to citizens and other levels within the health systems. 7) The EU should further help to standardise approaches on health data, in particular on data sharing and transfer in a more organised way.
- 8) Citizens should be more empowered on accessing and controlling their health data 9) Trusted Communication and collaboration between stakeholders dealing with data is essential - through dedicated platform, skills
- development, more collaboration.

