PANDEM-2

PANDEMIC PREPAREDNESS AND RESPONSE

Report on social, ethical and legal issues in pandemic preparedness planning

Deliverable D4.2

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List of acronyms and abbreviations

CDC	Centers for Disease Prevention & Control
COVID	Coronavirus Disease
EBM	Evidence-based Medicine
ECDC	European Centre for Disease Prevention & Control
ELSI	Ethical Legal & Social Issues
EU	European Union
FRA	European Union Agency for Fundamental Rights
GDPR	General Data Protection Regulation
HERA	European Health Emergency preparedness and Response Authority
IHR	International Health Regulations
MERS	Middle East respiratory syndrome
OECD	Organization for Economic Co-operation and Development
PANDEM	Pandemic Risk & Emergency Management (Grant agreement no 652868)
PANDEM-2	H2020 EU funded project Pandemic Preparedness and Response (GA no 883285)
PTSD	Post-traumatic stress disorder
RCCE	Risk Communication & Community Engagement
SARS	Severe Acute Respiratory Syndrome
SPI-B	Independent Scientific Pandemic Insights Group on Behaviours
UNESCO	United Nations Educational, Scientific and Cultural Organization
WHO	World Health Organisation
WP	Work Package

1. Executive Summary

This report documents the ethical, legal and social issues (ELSI) associated with pandemic preparedness and response. It is based on work undertaken as part of Task 4.2 'Social, Ethical and Legal Issues' in the PANDEM-2 DOA. A literature review was performed to identify the ethical, legal and social implications of pandemics and pandemic response measures. The review explored the following key issues: (i) the equitable distribution of resources, (ii) balancing individual rights and the public good; (iii) sharing of data and resources across organisations and geographic boundaries and (iv) the consideration of vulnerable groups. Disconnects between ELSI and the reality of current governance and policy on pandemic preparedness and response were highlighted, and recommendations were proposed on measures to mitigate or avoid any harms to societal values, or risks to fundamental rights. The report further outlines how the project addresses or does not generate further ELSI risks associated with pandemic preparedness and response. The ELSI identified include:

Ethical Issues

Ethical principles identified as important in the decision-making process during pandemic preparedness and response include individual liberty, proportionality, privacy and confidentiality, duty of care, reciprocity, fairness, solidarity, reasonableness, and transparency (section 4.2). It was evident from the literature that ethical issues are considered in existing pandemic plans. However, there is no consensus on which ethical frameworks should guide decision-making.

Legal Issues

Legal issues were identified relating to data sharing, the collection and processing of personal data, non-compliance with data protection legislations and human rights infringements resulting from mandatory measures such as restricted movements and gatherings, and mandatory vaccination (section 4.3). Although various guidance documents and resources exist to address these legal issues, some legislations have no enforcement mechanisms, while others have no formal sanctions or penalties associated with non-compliance. Previous pandemics also highlighted critical weaknesses in national public health and health emergency laws and legal capacities, thereby highlighting a need to strengthen countries' legal preparedness for future pandemics.

Social Issues

Identifying vulnerable groups and populations at risk is crucial for reducing the social gradient in health during a pandemic. The review focused on four main groups identified as priority vulnerable populations in the context of pandemics: persons of migrant origin, older adults, healthcare workers and people with disabilities (section 4.4). Within the literature, there was general agreement that social factors (e.g., income, education, occupation, and ethnicity) play a significant role in the severity of pandemics, with socially disadvantaged groups being at exceptionally high risk. Previous pandemics have however shown that these factors are often disregarded in national and international pandemic plans.

The findings from the review were discussed at a workshop with 26 stakeholders representing public health agencies, research institutions, epidemiologists, data scientists, communications specialists,

information technology experts, first responders and PANDEM-2 Advisory Board members. The proposed recommendations on how to mitigate ELSI risks during pandemic preparedness and response were also validated at the workshop. Following these activities, ten key recommendations are made in this deliverable.

Recommendations:

1. Develop an Ethics framework incorporating relevant ethical principles that need to be prioritised during pandemic preparedness and response

2. Messages should be consistent, clear and understandable; and communication should be done using culturally appropriate methods, with accessible materials tailored to various social groups

3. Risk communication and community engagement needs to clearly define vulnerable persons, be two-way, and engage local, regional and national partner organisations

4. Coordination with policymakers, influential social media leaders, local leaders, women and youth groups, religious and elders' groups, local and international NGOs, health experts and practitioners, volunteers, and people with experience of pandemic diseases is key in disseminating information to all

5. Misinformation should be addressed through media surveillance, feedback, emergency anthropology studies, and other social science tools

6. Educate communities about the complex realities of pandemics and good pandemic management, to enhance public understanding of pandemic decisions, and to promote receptivity and compliance with messages delivered by public health authorities

7. Legal policies concerning digital contract tracing apps should make provisions to address ethical and legal concepts including privacy and data protection, and outline clear steps on what to do in case of data breaches

8. National legislations concerning emergency responses should be consistent with international health regulations, to establish comprehensive and appropriate response procedures

9. IT systems and tools used for pandemic preparedness and response (such as predictive modelling tools, epidemic surveillance systems and contact tracing apps) should be constantly evaluated, updated, and re-evaluated to ensure that they are effective and meet appropriate ethical standards and legal requirements

10. Further research is required to inform the development and implementation of digital technologies and tools used for pandemic preparedness and response

The recommendations from this report will contribute to the work being done in other PANDEM-2 work packages including WP4 on resource planning and workforce allocation, WP5 on the

development of risk communication resources/training and WP6 on the demonstrations of PANDEM-2. Findings from the literature review will also inform WP3 on situational awareness, specifically the task on privacy, social and ethical impact assessments (Task 3.5).

2. Introduction & Background

2.1. Structure of this report

Section 2 defines the aim and relevance of this deliverable and provides a brief introduction to the PANDEM-2 project. It also summarises previous work that was done as part of the *PANDEM* project, which this deliverable builds on. Section 3 describes the methodologies that were adopted throughout the development of this deliverable, including (3.1.) decisions that informed the scope of the literature review; (3.2.) search methods that were used to identify ELSI relevant to pandemic preparedness and response in the literature and (3.3.) a workshop conducted with Advisory Board members and other stakeholders to discuss and validate recommendations on how to address and mitigate any ELSI risks associated with pandemic preparedness and response. Findings from the literature review are presented in Section 4. Section 5 presents recommendations from this deliverable, with a discussion on their applicability to PANDEM-2, and a conclusion.

2.2. Aim of this deliverable

This report outlines key ethical, legal, and social issues (ELSI) associated with pandemic preparedness and response, and highlights discrepancies between these issues and the reality of current governance and policy on pandemic planning. Measures that can be taken to prevent or mitigate ELSI risks during pandemic preparedness and response are recommended. The report also discusses ELSI that apply to specific pathogens relevant to the PANDEM-2 project, and outlines how the project could potentially address current risks, or not generate further ELSI risks.

2.3. Overview of PANDEM-2

The PANDEM-2 project aims to implement novel concepts and IT systems to improve European countries' capacity for pandemic preparedness and response. PANDEM-2 will facilitate and demonstrate the capture and integration of pandemic-relevant data from numerous sources, including participatory surveillance systems such as InfluenzaNet, and social media (e.g., Twitter and Reddit). This data will be accessible and analysed via an online dashboard, designed to support the needs of pandemic managers (public health agencies responsible for pandemics), hospital managers and first responders in Europe. The PANDEM-2 dashboard will also facilitate predictive modelling of infection rates and spread, resource management and mapping of workforce capacity. The overall aim is to assist relevant authorities to make rapid, evidence-based decisions in response to a pandemic, and to supply them with the resources needed to communicate these decisions effectively to their citizens.

2.4. Previous work in PANDEM

This deliverable builds on previous research from the Pandemic Risk and Management project (PANDEM; Grant Agreement: 652868) (*PANDEM D4.2*), which assessed national and international pandemic preparedness plans in the EU and explored how ethical and human rights aspects had been

considered in these plans (available on the PANDEM-2 website here: https://pandem-2.eu/wp-content/uploads/2020/12/D4.2-PANDEM-Ethics-and-Human-Rights_FINAL.pdf). Results from a thematic analysis of the national pandemic preparedness plans of seven EU Member States (Croatia, Czech Republic, France, Hungary, Italy, Spain, and the UK) found that the incorporation of ethical considerations was limited, with four of the countries (Croatia, Hungary, Italy and Spain) making no reference to ethical issues in their plans. This lack of recognition was apparent both at national and international level, as evident in some international guidance documents on pandemic planning where ethical considerations were either not referenced (e.g., the 2005 EU Pandemic Influenza Preparedness and Response Plan (Commission of European Communities, 2005)) or not prioritised (e.g., the 2005 WHO checklist for influenza pandemic preparedness planning (WHO, 2005b)).

A literature review conducted as part of *PANDEM D4.2* identified ethical and human rights issues in pandemic preparedness and response. Findings from this review were clustered into four main themes which were: (i) Communications; (ii) Surveillance; (iii) Isolation, quarantine, border control & social distancing and (iv) Equity and prioritisation of healthcare resources. While there was considerable literature addressing ethical issues associated with the allocation of scarce resources, studies on ethical considerations associated with pandemic communication and surveillance were limited, and the academic evidence was not always reflective of themes central to pandemic preparedness planning. These findings, alongside key recommendations proposed from the *PANDEM D4.2* review (see figure 1 below), will inform the focus of this deliverable.

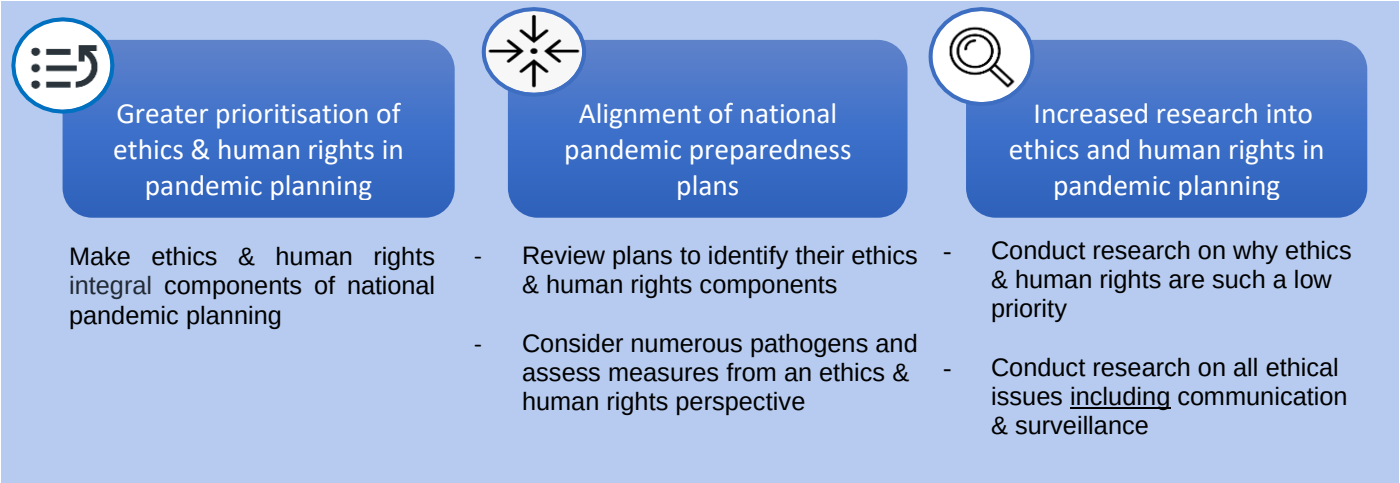


Figure 1: Recommendations on ethics and human rights considerations in pandemic preparedness and response (PANDEM D4.2)

2.5. Relationship with other deliverables

The recommendations from this report will contribute to the work being done in other PANDEM-2 work packages including WP4 on resource planning and workforce allocation, WP5 on the development of risk communication resources/training and WP6 on the demonstrations of PANDEM-2. Findings from the literature review will also inform the PANDEM-2 task on privacy, social & ethical impact assessments (Task 3.5).

3. Approach

This section provides details of the work that was carried out as part of *WP4*, *Task 4.2 Social, Ethical and Legal Issues in Pandemic Planning and response*.

3.1. Literature Review Scope

This review aimed to explore the ethical, legal, and social impacts of pandemics, and how societal and fundamental rights might be impacted by pandemic preparedness and response. Priority topics for the review as set out by the project's task description in the Grant Agreement were:

(i) The equitable distribution of resources
(ii) Balancing individual rights and the public good
(iii) Sharing of data and resources across organisations and geographic boundaries; and
(iv) The consideration of vulnerable groups

The focus of the review was also informed by discussions with end-users and PANDEM-2 project managers. These discussions were centred around the findings from the *PANDEM D4.2* literature review, as described in section 2 above (see Appendix A). It is important to note that *PANDEM D4.2* was conducted before the COVID-19 pandemic, while this report (PANDEM-2 D4.2) includes literature and findings from the pandemic period.

3.2. Search strategy

Searches were conducted on three databases – PubMed, Embase and Google Scholar. Search terms were developed for PubMed (see Table 1) and translated onto the other two databases. Database searching was supplemented with manual searching to identify additional studies and relevant grey literature. Initial searches were conducted between Nov 2021 and April 2022, and then updated between May and July 2022.

Table 1: Search terms for ELSI in pandemic preparedness and response

Keyword	Search terms
1. Ethics	"ethics" OR "ethical" OR "ethic" OR "ethicist" OR "ethically"
2. Legal	"legal" OR "law" OR "laws" OR "lawful" OR "legislative" OR "constitutional"
3. Social	"social" OR "society" OR "societal"
4. Issues	"issues" OR "concerns" OR "considerations" OR "requirements" OR "impacts" OR "frameworks" OR "guidelines" OR "regulations" OR "recommendations"
5. Pandemic	"pandemic*" OR "epidemic*" OR "outbreak*"
6. Preparedness/planning	"preparedness" OR "planning"
7. Response	"response" or "disaster response" OR "risk management"

Search string: (1 OR 2 OR 3) AND 4 AND (5 AND (6 OR 7))

Inclusion criteria for the review were:

(i) Peer-reviewed and grey literature
(ii) Studies addressing ethical, legal or social issues in pandemic planning and response
(iii) Studies published in or translated to English language

3.3. Development and validation of recommendations

Following completion of the literature review, the project team drafted recommendations on how to mitigate ELSI risks during pandemic preparedness and response, based on the findings of the review and their professional expertise. A workshop was then conducted with members of the PANDEM-2 consortium, to discuss the literature review findings and validate the proposed recommendations. The workshop took place virtually via Zoom, on the 13th and 14th of July 2022. It was led by Trilateral Research and was attended by 26 participants in total. Participants represented research authorities, public health agencies, epidemiologists, data scientists, communications specialists, information technology experts, first responders and PANDEM-2 Advisory Board members. The workshop agenda and questions discussed can be found in Appendix B. In brief, workshop participants were invited to consider the relevance, content, clarity and feasibility of each recommendation, and any relevant applications for the PANDEM-2 project. Snapshots from one of the group discussions are also shown in Appendix B.

4. Results

This section presents findings from the literature review on ELSI in pandemic preparedness and response.

4.1. Literature search results

The database searches yielded 1148 records, 440 of which were removed as duplicates. 451 articles were excluded following title and abstract screening and 23 were further excluded after full-text screening, leaving 234 articles for inclusion in the review. Findings on ethical issues are discussed in section 4.2, legal issues in 4.3 and social issues in section 4.4. Some issues had cross-cutting implications (e.g., ethical and legal aspects), and are discussed in more than one section.

4.2. Ethical issues in pandemic preparedness & response

Pandemic outbreaks have gained significant public attention in recent years and there is increasing acceptance of the importance of considering ethical implications during pandemic planning. Public health experts have begun reflecting on the extent to which previous preparedness plans have been helpful, where problems have occurred, and what aspects have been neglected in pandemic planning; and various initiatives have been launched in this regard. One prominent example of such initiatives is the *'Independent Panel for Pandemic Preparedness and Response' (2021)* initiated by the WHO, where ethical issues were highlighted as central to pandemic planning.

Various ethical frameworks have been proposed to guide decision-making during pandemic planning, (e.g., Fielding et al., 2021; Kass, 2005; Thompson et al., 2006; Upshur et al., 2005; WHO, 2007), each based on a different set of ethical values. Figure 2 below summarises the main ethical principles that were identified as relevant to pandemic preparedness and response from PANDEM-2 D4.2 literature review. Several authors have commented on the lack of consensus on an ethical framework to guide decision-making during pandemic planning, and how this challenges the ability to adopt a coherent and consistent approach towards preparing for, or responding to a pandemic (O'Sullivan et al., 2022; Rubio et al., 2020; Thompson et al., 2006). The lack of this framework also makes it difficult to decide what ethical values to prioritise, especially as some ethical values conflict with each other (Robert et

al., 2020; O'Sullivan et al., 2022). The need for an ethical framework to guide decision-making during pandemic preparedness and response at EU level was previously identified in the *PANDEM D4.2* report. No such framework was identified at the time of this review. This need is therefore re-emphasised in this deliverable.

Figure 2: Ethical principles relevant to pandemic preparedness and response

The sections below discuss ethical issues as they apply to the distribution of resources and the prioritisation of public good vs individual rights during pandemics.

4.2.1. Equitable distribution of resources

Resource allocation is ethically challenging even in non-emergency situations. It is even more complex in the context of a public health emergency, where decisions are time-sensitive, information is rapidly changing, and there are significant risks of harm (Steele & Duthie, 2021). In a pandemic where medical resources such as medication, personal protective equipment, ventilators, etc tend to become scarce, there is usually a need to prioritise certain groups over others. Meanwhile, the process of deciding

who to prioritise and determining what ethical principles should guide this decision remain unclear. Various studies have identified that no single ethical value is sufficient on its own to determine which patients should receive scarce resources (Emanuel et al., 2020; Persad et al., 2009; Rosenbaum, 2011). The decision-making process therefore requires balancing multiple ethical values to ensure that the allocation process is fair and consistent. Ethical concepts associated with the distribution of scarce resources in a pandemic are discussed below.

4.2.1.1. Utilitarianism vs autonomy

A widely embraced ethical principle for allocating life-saving resources when there are shortages is to try to maximise public health benefit by saving as many lives as possible (Savulescu et al., 2020). This utilitarian approach emphasises population outcomes, with the best course of action being determined by the benefit achieved by the greatest number of people. This conflicts with non-utilitarian views that emphasise the paramount value of each human life (Emanuel et al., 2020). Hence, decision-making following a utilitarian model is established at population level, at the expense of individual autonomy, which is a fundamental principle of society's medical ethics.

An example of the utilitarian approach was seen during the COVID-19 pandemic, where non-emergency surgical procedures were postponed, to prioritise patients with COVID-19 (Brown et al., 2021). While the moral grounding for such a decision seems reasonable in a resource-limited context, the downstream effects of prolonged postponement could be severe (COVIDSurg Collaborative, 2020). For example, a cancer patient could risk a significant change in prognosis if their surgery is delayed (Brown et al., 2021). As such, prioritising patients with COVID-19 over patients with non-urgent but time-sensitive medical conditions may not always yield the utilitarian aim of providing the greatest net benefit for the largest number of patients. While acknowledging that the context of limited resources during a pandemic is an important issue to consider, Brown et al. (2021) suggest that more equitable decision-making can be formed by analysing ethical dilemmas during pandemics through the lens of the four pillars of medical ethics – beneficence, non-maleficence, autonomy, and justice. They propose that this approach could promote a more ethical distribution of available resources by providing a clear framework for evaluating when a patient's right to autonomy should or should not take precedence over public health needs.

4.2.1.2. Using predictive modelling for resource allocation

Predictive modelling in the healthcare context is a process that applies available data to identify persons who have high medical needs and face high risks of needing medical services (Vogenberg, 2009). Predictive models can be used to forecast future events, making it possible to harness available data to improve health, and reduce healthcare costs. Thanks to technological advances regarding data availability, diminishing costs of data storage and increased computing power, such developments make large-scale risk assessments feasible, to help inform preventive public health approaches. Predictive modelling systems have proven useful in pandemic contexts where decisions need to be made quickly. They are also useful in helping to prioritise scarce resources (van Der Schaar et al., 2021). However, their use also raises some important ethical considerations. For example, these systems are often used to automate decision-making processes that were previously made by humans, which introduces ethical challenges relating to accountability and value judgments (Peters et al., 2020). They also often require a lot of personal data, which has implications on privacy, consent, and security

(Kroll, 2018). Trustworthiness is another known challenge, stemming from the risks of misclassification and dependence on assumptions (Angehrn et al., 2020). The complexity of these data-driven algorithms also makes it difficult to communicate concepts and results to patients and the general public, and to assess ethically relevant factors such as the robustness of results and unintended biases (Wynants et al., 2020). The benefits of predictive modelling systems could therefore be outweighed by the risks if they are not ethically designed and deployed. Cave et al. (2021) refer to the four pillars of biomedical ethics as a useful lens through which these challenges can be identified and addressed. These are beneficence (the moral obligation to act for the benefit of others), non-maleficence (the obligation to not inflict harm on others), autonomy (the right for individuals to make decisions about their own health) and justice (the principle of treating others fairly). They further emphasise the importance of open and transparent communication with diverse stakeholders during the development of these modelling systems, to ensure that they are ethically compliant.

4.2.1.3. Justice

Distributive justice, which is understood to be the fair and appropriate distribution of benefits, risks and costs within a society (Fisher et al., 2020), provides moral guidance for processes that affect the distribution of resources during a pandemic. It is a derivative of the principle of justice, which, as earlier mentioned, is one of the four pillars of bioethics that underpin modern medical practice (Beauchamp, 1994). In a pandemic situation where resources are in short supply, decisions need to be made to allocate chances of survival and mortality risks, and this requires that resources be accessible to individuals according to need and within the context of resource availability (Savulescu et al., 2020). The bases for these decisions need to be both ethical and just.

Scenarios have been described from previous pandemics where the principle of justice was violated, such as during medical triage (Spieker, 2021). Examples of these include discrimination (e.g., based on age); quantification (e.g., sacrificing one patient's life over another to maximise benefit) and using a utilitarian approach, which, as described in 4.2.1.1. above, often violates patients' autonomy (Spieker, 2021). Some ethicists purport that the utilitarian view is ethically justified when resource allocation takes into consideration the number of years lived by a patient, their quality of life and the cost incurred by the health system (Marseille & Kahn, 2019; Savulescu et al., 2020). However, it has also been argued that this perspective only recognises those who have a life 'worthy' of being lived, and may marginalise weaker social groups in society, such as the elderly, the disabled and the poor (Palazzani, 2020). Noting that no one ethical value can underpin the design of a fair distribution system in the context of scarce resources, Yip (2021) proposes that an ethically justified distribution process must aspire to achieve three goals: (1) optimal efficiency in decision-making such that resources are dedicated to those most at risk; (2) equity, by treating all patients in a similar manner; and (3) prioritisation, such that resources are available to patients most in need at any given time. In line with this, benefits can be maximised by prioritising high-risk patients likely to survive longest after treatment (Emanuel et al., 2020). Monteiro (2020) further emphasises that a solution for distributive justice is always more suitable if planned ahead of time, rather than when decided during an emergency.

4.2.1.4. Duty to provide care

The strain on health services following a pandemic necessitates the rationing of resources – including human resources, i.e., staff available to provide care to patients. The notion that health professionals

have a duty to care for patients is fundamental to the functioning of health systems. As part of this commitment, health professionals have to accept having to expose themselves to some level of risk in order to provide patient care (Thompson et al., 2006). During previous pandemics such as SARS and Ebola, there was a consensus that appropriate safety measures had been taken to protect healthcare workers, and that risks of them getting infected were low (Dwyer & Tsai, 2008; Emanuel, 2003). However, given the scarcity of protective equipment during the COVID-19 pandemic, in addition to the mode of transmission and asymptomatic nature of the disease, questions around healthcare workers' safety became a focus of ethics discussions. Healthcare workers face significantly high risks of getting infected, which could also have serious implications on the health of their families and households (McConnell, 2020). In addition, first line responders usually face high security risks from pandemics – especially those caused by deadly diseases such as Ebola – as they are typically exposed to the disease in their duty of care, before being correctly informed about the nature of the risks involved and how to protect themselves. Fins & Miller (2020) note that less attention has been paid to whether there is a limit to practitioners' obligations with respect to providing care to patients during a pandemic. Instead, there has been a tendency to applaud practitioners who placed themselves at selfless risk as heroes. The authors further point out that approaching medical ethics from the perspective of heroism is neither sustainable nor robust enough to meet the complexities of emergency situations during a pandemic. McDougall et al. (2021) propose balancing the duty to provide care against other ethical considerations such as healthcare providers' well-being, as an ethical approach to staff safety. This is particularly important as patients face a risk of suffering harm if healthcare staff are physically or mentally unable to perform their jobs. The topic of mental wellbeing for healthcare professionals in the context of pandemics and pandemic preparedness planning is further discussed in Section 4.4.

4.2.1.5. Proportionality

Proportionality has been referred to as a 'corrective' principle, in that it has the potential to clarify and set limits on what is beneficial and what is harmful, especially when some ethical values are in conflict. This principle requires that different ethical considerations be balanced, and that even where it is not feasible to eliminate all risks involved, the benefits should outweigh the burdens. As highlighted by Isaacs et al. (2020), the uncertainty and shifting circumstances during a pandemic can make responsible planning and allocation of resources difficult. Proportionality can inform decisions around rationing of limited resources, such that the goal of saving as many lives as possible is balanced against the impacts on the rights of individuals (Boyd, 2020), or particular groups (Elves & Herring, 2020). Proportionality can also inform how much risk is appropriate for health workers to assume in the pursuit of saving lives. For example, an expectation of heroism as mentioned in 4.2.1.4 above assumes that clinicians should take on a disproportionate burden at the risk of their own health (and lives) when dealing with a pandemic (Fins & Miller, 2020). Proportionality provides a means to redistribute the burdens of care more equitably, such that health professionals are not required to be heroes to practise ethically. Another important issue addressed by the principle of proportionality is communication during pandemics. Scholars and healthcare guidelines have outlined that messages should be clear, simply explained and reflective of decisions taken, as well as decision-making processes (including both benefits and risks) in order to avoid misunderstandings (Boyd, 2020; Smith et al., 2021; WHO, 2005a). Messages should also be accurate and acknowledge uncertainties, without giving baseless reassurances (WHO, 2005a).

4.2.2. Balancing the public good vs individual rights

Pandemics bring tensions between individual rights and the public good, as many response measures which are useful in protecting public health (e.g., restricted movement, contact tracing and mandatory vaccination), evoke opposition by individuals who feel that these measures infringe on their freedom and rights. Ethical concerns associated with these measures are discussed below.

4.2.2.1. Surveillance

Surveillance refers to the continuous and systematic collection, analysis and interpretation of health-related data (e.g., case numbers, death rates, reproductive rates, etc) for the purpose of planning, implementing and evaluating public health practice (Nsubuga et al., 2006). It constitutes the foundation of pandemic response and is a necessary process adopted by public health authorities to trace the spread of pathogens across regions and nations (Fairchild et al., 2017). While the need for surveillance is justified for epidemiological purposes, the use of surveillance measures during health emergencies has fuelled discussions about the limitation in citizens' rights and raised ethical and legal concerns on data usage, data protection, and privacy (Van Kolfschooten & de Ruijter, 2020). In its international guidelines on public health surveillance, the WHO identified that surveillance could trigger concerns about intrusion of privacy and discrimination, especially when conducted without public knowledge or consent (WHO, 2017).

Contact tracing apps are an example of a surveillance system used widely to aid pandemic management. Findings from a large-scale study across seven European countries revealed concerns about the use of the COVID-19 contact tracing app, mostly due to loss of privacy and heightened control (Lucivero et al., 2020). Statements were made conveying a sense of fear and danger in relation to these apps, such as 'Big Brother', 'witch hunt', 'living like in prison', and people being 'programmed' (Lucivero et al., 2020). There are also reports that contact tracing might to some extent be in violation of the legally enshrined duty of medical secrecy (Cho et al., 2020). Debates on this subject contend that the clinical ethical framework which emphasises medical secrecy in the patient-physician relationship conflicts with the public health ethical framework where the provision of some sensitive medical information is deemed proportionally relevant for minimising infection, hospitalisation, or deaths (Cho et al., 2020). Another commonly expressed concern about contact tracing apps is their stigmatising potential, as they identify people who have or have had COVID-19 (Williams et al., 2021). Data privacy and security were also key issues reported by a study in the UK, with interviewees showing reluctance to have their data accessed by government or health authorities (Williams et al., 2021). The use of drones to monitor social distancing or curfews during COVID-19 also caused suspicion among individuals, as their privacy rights were interfered with (Baudouin, 2021).

The success of surveillance measures relies on the widespread adoption of tracking technologies (Parker et al., 2020). This is in turn dependent on the public being convinced that these technologies will be implemented responsibly, and that data will be handled ethically. Some useful resources have been developed in this regard, such as a framework proposed by Ranisch et al. (2021) outlining some important ethical considerations when planning and implementing a contact tracing app (see table 2). The authors highlight that this is not a complete list and highlight that all pandemic management strategies involve several trade-offs. There is also guidance from the WHO on the ethical and

appropriate use of contact tracing technologies (WHO, 2020a), and a roadmap developed by Lanzing (2021) for the ethical evaluation of contact tracing apps.

Table 2: Ethical considerations when planning and implementing a contact tracing (CT) app

Substantive values to be considered:

Public Health Benefit:
- Is the pandemic situation such that contact tracing activity is motivated from a public health standpoint?
- Is the pool of potential users who are willing to use a CT app large enough for epidemiological effectiveness?

Privacy:
- Are measures in place for data protection and against data loss or misuse?
- Are data security authorities involved?
- Is collection of the tracing-data temporary (e.g., will it be deleted after a certain, specified amount of time)?

Justice:
- Has accessibility and availability been maximised?
- Are benefits and burdens of CT apps equally distributed among the population?

Autonomy:
- Are CT apps used voluntarily? Are users able to withdraw consent?

Solidarity:
- Has consideration been given to whether negative attitudes towards people who do not use the app may feed into practices of victim blaming?

Procedural values to be considered:

Transparency:
- Are technological solutions and frameworks sufficiently transparent (e.g., open source)?

Proportionality:
- Are social, and moral costs of CT apps proportionate to the pandemic threat and the expected effectiveness of using the app?

Trustworthiness:
- Are democratic procedures in place to guide decision making? Can population uptake be assumed?

Reasonableness:
- Is there sufficient evidence that the CT app meets technical standards of reliance?

4.2.2.2. Mandatory Vaccination

The ethical appropriateness of vaccination policies depends on various factors including disease severity, vaccine effectiveness and safety, target populations, as well as social, cultural, and political considerations (WHO, 2022a). Mandatory vaccination policies have historically been more widely accepted in emergency situations where there are imminent threats to health (Gur-Arie et al., 2021), (Savulescu, 2021). However, the ethical guidance on vaccine mandates suggests that mandates should only be implemented after all other reasonable means have failed (or are likely to fail) to increase vaccine uptake, and/or reduce disease transmission by other means to an acceptable level (WHO,

2022a). Such was the case with COVID-19, where vaccine hesitancy was a major challenge, predominantly fuelled by concerns about the safety, efficacy, real benefit for non-vulnerable groups, and long-term profile of the vaccines. In response, governments worldwide introduced mandatory vaccination as a requirement to gain access to certain public places such as bars, restaurants, gyms, theatres, etc. Vaccination was also made mandatory for travel and work purposes (e.g., for first line health care staff).

Tensions arose from the decision to mandate vaccination for healthcare workers, which also highlighted some conflicting ethical values (Gur-Arie et al., 2021; Olick et al., 2021; Parker et al., 2021). For example, in early 2022, unvaccinated healthcare workers in England faced a threat of being sacked if they did not get vaccinated (Wylie, 2022). There is no doubt that healthcare providers are committed to putting patients first. However, they also have the fundamental right of autonomy to make voluntary informed decisions about their own health, including refusing unwanted medical interventions. In this case, respecting the principle of autonomy limits the duty to accept vaccination for the benefit and protection of others, and is a shield against any mandate that overrides individual choice (Olick et al., 2021). However, less vaccination equates to more sick days and possibly staff shortages, amidst strained resources and high admission rates, which endangers patients' lives. In the balancing of principles and consequences therefore, institutions are required to take decisions that maximise immunisation coverage, while also minimising infringement on healthcare workers' rights of autonomy and informed consent (Olick et al., 2021).

Vaccination mandates may also contribute to increasing discrimination between society groups, due to non-vaccinated people being refused access to specific places, services, or activities (Bardosh, 2022). This may disproportionately affect already marginalised groups, such as those already facing barriers in accessing services. The WHO advises that efforts be made to demonstrate the benefit and safety of vaccines to encourage acceptance, and that stricter regulatory measures be considered only if these means are not successful (WHO, 2022a).

4.2.2.3. Restriction of movement

Lockdowns, mandatory quarantine, and border control are some examples of ways in which people's movements have been restricted in response to a pandemic, to curb the spread of the pandemic disease. These measures also highlight ethical tensions between the collective good and individual rights and require that considerations be made on the extent to which individual rights and freedoms can justifiably be restricted in order to achieve intended public health goals (Bayer, 2007; Smith & Upshur, 2019). In the same line with vaccine mandates, these mandatory measures should only be instituted as a last resort, when voluntary measures cannot reasonably be expected to succeed, or when the failure to institute these measures is likely to have a substantial impact on public health (Smith & Upshur, 2019).

Key messages on ethical issues:

It is generally agreed that care should be provided in as equitable a manner as possible during pandemics, and that decision-making processes for resource allocation should be reasonable, transparent, and underpinned by ethical principles such as fairness and justice. However, to ensure consistency and accountability in responding to pandemics, preparedness plans need more than a

commitment to acting reasonably and with transparency. Various frameworks exist that address the equitable distribution of resources and the prioritisation of public good vs individual rights (see appendix C). However, these frameworks are developed from different sets of ethical and moral standards. There is a need for a value-based decision-making framework that clarifies what ethical values should be prioritised during pandemic preparedness and response, to attain consistency and transparency across countries.

Secondly, the benefits of measures such as surveillance and mandatory vaccination in protecting public health are well recognised. However, while acknowledging that there are national legislations that establish a duty to conduct surveillance, which also set restrictions on their implementation, it is important to note that 'legal' does not also equal 'ethical'. It is therefore essential to consider the ethical implications of pandemic response measures, including the potential value conflicts that they may bring about. Measures that violate individual rights should also only be instituted as a last resort, when voluntary measures cannot reasonably be expected to succeed, or when the failure to institute these measures is likely to have a substantial impact on public health. This should be combined with clear and understandable communication explaining the reasons why these measures have been taken, recognising that this inevitably limits individual rights, but emphasising the exceptional and temporary nature of the measures taken.

4.3. Legal issues in pandemic preparedness & response

The importance of legal preparedness during pandemic preparedness and response is well recognised. During emergency situations, laws could authorise certain actions that would otherwise not be permitted, thereby allowing more flexible responses to improve public health. However, there are important legal considerations to make when preparing for or responding to pandemics. These legal issues are discussed below, as they apply to the sharing of data and resources, current governance and policies, basic human rights and government support schemes.

4.3.1. Sharing of data and resources across organisations & geographic boundaries

Data sharing plays a critical role in the development of public health responses and is a valuable part of the pandemic preparedness and response process. An example of the importance of data sharing can be seen from the response to the SARS-CoV-2 pandemic, where sequencing results of the viral genome shared by Chinese scientists became instrumental to the development of the COVID-19 vaccine (Cohen, 2020). Another example is the creation of the COVID-19 Data Portal by the European Commission, which allowed researchers around the EU to collect and share new data regarding COVID-19 (Harrison et al., 2021). By allowing for the rapid open sharing of data, the platform served as an effective measure to support the monitoring and management of the pandemic. Other benefits of data sharing include an increase in cooperation and transparency between organisations around the world, an increase in knowledge about health issues, and acceleration in research which could create effective health programmes for the global population (European Commission, 2020a; Van Panhuis et al., 2014). Investing in data sharing systems will be beneficial for public health agencies, as sharing information on interventions, transmission, cases, deaths, etc between countries will leave them better equipped to tackle public health threats (Kupferschmidt, 2014).

The General Data Protection Regulation provides rules and regulations for data protection and privacy in the European Union and the European Economic Area (Voigt & Von dem Bussche, 2017). It serves as the legal basis for public bodies involved in collecting, sharing, and processing data. Specific types of personal data (such as health data, biometric information, genetic data, data concerning a person's sex life or sexual orientation or data revealing racial or ethnic origin, political opinions, or religious beliefs) are subject to additional protection under the GDPR, as outlined in Article 9 (Voigt & Von dem Bussche, 2017). According to this guidance, health data can only be processed if it serves the interest of public health and protects from cross-border health threats. The GDPR increases transparency and gives individuals rights such as the right to access, rectify or erase their personal data. Failure to comply with GDPR regulations, such as through violation of privacy and security rules, can result in penalties and hefty fines (Voigt & Von dem Bussche, 2017). Organisations processing health data must therefore follow strict regulations to ensure GDPR requirements are met. However, several governments around Europe faced criticism for not adhering to data protection rules and regulations during the COVID-19 pandemic.

In 2020, the Croatian government came under fire from critics after proposing a law, known as the Electronic Communications Act, that would allow authorities to track and monitor the phones of individuals undergoing self-isolation (Vladisavljevic, 2020). In Bulgaria, an amendment was proposed to the Electronic Communication Act which would have allowed the police permission to access traffic data to ensure that individuals were following mandatory isolation regulations. However, this was deemed illegitimate by the Constitutional Court, as it was invasive to individual privacy (EU-FRA, 2020). Germany launched the Luca app for the public, to help with contact tracing during the COVID-19 pandemic. In January 2022, German police came under intense scrutiny by privacy advocates and the public after they used the Luca app to help track down witnesses in an investigation (Pannett, 2022). Under Germany's strict data protection regulations, the data on the app should not be accessed by non-health authorities or used in investigations. In 2020, the Data Protection Commission stated that the Wexford County Council in Ireland failed to comply with national and EU data protection laws when they used drones to monitor public movement during the lockdown (Brennan & McConnell, 2020). The council started using drones to monitor illegal dumping, and to monitor holiday homes and caravan parks to ensure compliance with quarantine measures (Brennan & McConnell, 2020). A data protection impact assessment which is usually completed for projects which have privacy issues or complications, was not carried out before the project. While acknowledging that the collection and sharing of health data between countries is a useful way of getting better equipped for future pandemics, data protection and privacy issues need to be tackled, such that these processes meet all necessary legal requirements.

There are also legal issues around the use of open-source health data. For one, it is important to ensure that the data uses anonymisation/pseudonymisation techniques to reduce the risk of identification before making the data accessible to anyone (Rodriguez et al., 2022). Article 6 and 9 of the GDPR contain legal information related to the processing of health data for research purposes (Voigt & Von dem Bussche, 2017). Although anonymised data (where you cannot possibly identify individuals) is not subject to the GDPR, pseudonymisation is regarded as an additional safeguard which needs to be used in scientific research to ensure compliance with the principle of data minimisation

under Article 89 (Voigt & Von dem Bussche, 2017). The European Data Protection Board (EDPB) stresses that data protection rules such as GDPR do not hinder measures taken in the fight against pandemics, and that even in these exceptional times, data controllers must ensure the protection of personal data and considerations should be taken to guarantee the lawful processing of personal data (European Data Protection Board, 2021).

4.3.2. Current governance and policy

In times of crisis such as during pandemics, public governance matters more than ever. Governance arrangements play a critical role in countries' immediate responses to pandemics and continue to be crucial to recovery once a crisis has passed. An example can be seen from the rapid development of vaccines against COVID-19, which was considered an 'extraordinary achievement' (OECD, 2021). However, as previously discussed, successfully vaccinating the global population presented many challenges, from production to distribution, deployment, and importantly, acceptance. Trust in the vaccines is vital and critically dependent on good governance – that is, the ability of governments to communicate the benefits of vaccination, and to deliver the vaccines safely and effectively (OECD, 2021).

Global governance during pandemics has been heavily influenced by evidence-based medicine (EBM) and reinforced by particular groups of actors, including policymakers, politicians, and the medical community. As such, pandemic-related policy is often dominated by biomedical knowledge and practice (Salajan et al., 2020). This system primarily bases evidence on systematic reviews of randomised controlled trials, which are classed as the 'gold standard' of evidence. This is followed closely by meta-analyses (systematic reviews that use quantitative methods to summarise the results of trials). Meanwhile, expert opinions are regarded as the lowest category of evidence (Kamradt-Scott, 2012). While acknowledging that scientific evidence plays a critical role in the policy dialogue, the problem is that EBM biases pharmaceutical-based measures (such as vaccines and antiviral medications) which can easily be tested and evaluated by the 'gold standard' methods, over other public health interventions such as face masks, hand washing and social distancing measures. In addition, resulting policies tend to promote vaccines and antiviral medication as the ultimate indicator of pandemic preparedness, which downplays the importance of other legitimate public policy responses and pays inadequate attention to the weak capacity of many health systems (Kamradt-Scott, 2012). There is also less focus on educating the population to improve their understanding of the complex biological reality and the basic principles of good crisis management, which is equally an essential aspect of controlling an ongoing pandemic and an efficient way to prepare for a future pandemic crisis.

The COVID-19 pandemic for example, highlighted critical weaknesses in the public health and health emergency laws and legal capacities of several countries, often rooted in rudimentary and outdated laws that hampered response efforts (WHO, 2021a). It also underlined the impact of other legal frameworks on health emergency preparedness and response, such as those underpinning the health system and access to health services, and those beyond health, such as those influencing overall governance. The WHO identifies that there is a need to capture the lessons from COVID-19 and consider opportunities to strengthen countries' legal preparedness beyond COVID-19. They also suggest that effective pandemic responses require comprehensive advance planning efforts that include assessments of complex legal issues and authorities. Four factors have been identified as core

concepts for a comprehensive public health legal preparedness plan: laws, competencies, coordination, and information (Benjamin & Moulton, 2008). Laws must be based on contemporary legal principles by individuals who can apply this to public health goals (Martin, 2008). They can help facilitate transparent, consistent, and sound decision-making among health-care entities and practitioners during responses and may provide important liability protections during emergencies (Courtney et al., 2014). Lee (2020) adds that open communication about challenges faced by the government can encourage civic contribution to solutions, where bottom-up community-led initiatives can complement the work of government. Educating communities about the severity of pandemics and the complexities of pandemic management is another critical factor that can enhance public understanding and hence, receptivity and compliance with messages delivered by public health authorities (WHO, 2021c).

4.3.3. Mandatory measures and legal rights

As described earlier, various mandatory measures were introduced in European countries to reduce or limit the transmission of pandemic diseases. These measures are often accompanied by sanctions for persons not abiding with the restrictions, ranging from fines to imprisonment. There have been some negative reactions by the public in relation to some of these mandatory measures, with people expressing that their personal rights were being violated. Using examples from COVID-19, the sections below discuss legal rights infringements caused by restricted movements, mandatory vaccination, and surveillance systems. Important legal considerations for future pandemic preparedness planning are also highlighted.

4.3.3.1. Restrictions on movement and large-scale gathering

Restraint is an act carried out with the purpose of restricting an individual's movement, liberty and/or freedom to act independently (Equality & Human Rights Commission, 2019). An act of restraint must comply with basic legal principles, and there must be a legal framework governing its use. The rules and safeguards in the legal framework must also be sufficient to guarantee against the risk of abuse or interference with individuals' rights and should prevent any risks to health and well-being (Equality & Human Rights Commission, 2019). It is therefore important for pandemic plans to consider the legality of human rights restrictions.

The Health (Amendment) Act 2021 in Ireland set mandatory quarantine for individuals coming into the state from specific areas known to have high risks of COVID-19 transmission, or any variant of concern (Houses of the Oireachtas, 2021). Persons found guilty of an offence under this act could be given a fine (€2,000) or imprisoned for up to one month. An incident occurred in 2021, where a woman's father died on the day she entered mandatory hotel quarantine and she was denied permission to visit her father (Molloy, 2021). In its decision letter, the Department of Health stated: 'The attendance at a parent's funeral or in the aftermath of their death does not amount to an exceptional or urgent humanitarian reason which would make it necessary and proportionate to end the applicant's quarantine' (Molloy, 2021). Referring to the health system as 'heartless', the woman described the experience as 'dehumanising' and showing a lack of empathy and disregard for people's lives and personal circumstances. The imposition of mandatory hotel quarantine on international travellers has also been criticised for being discriminatory, unjustifiable, and amounting to a breach of Article 5 of the European Court of Human Rights (PGMBM, 2021).

Similarly, Germany's COVID-19 legislation (The Ordinance on Coronavirus Entry Regulations (Coronavirus-Einreiseverordnung – CoronaEinreiseV) came into force in September 2021 and regulates a uniform, nation-wide obligation to register, quarantine and provide proof, as well as a ban on carriage from areas of variants of concern (Federal Ministry of Health, 2022). As with Ireland, persons aged 12 or over had to possess a negative test result or proof of vaccination or recovery when entering the country for a period of time. Administrative fines (up to €25,000) could be given to those who broke the rules (Federal Ministry of Health, 2022). Members of the general population in Germany have been protesting restrictions and vaccination mandates, expressing that their personal freedom is being threatened (Hill, 2022).

In addition to regulations which affected individuals from entering into a country, several countries imposed limits on the number of people attending social gatherings and introduced legislations that brought in lockdowns and mandatory isolation. There have been reports of protests against these restrictions in several countries, e.g., in England, France, Germany, Canada, the USA, Croatia, Norway, etc (see figure 3) (Bardosh et al., 2022; Dyer, 2022; Kowalewski, 2021; Paterlini, 2021).

Figure 3: Protests against restrictions on movement and large-scale gatherings (Darragh, 2021; Hermann, 2020; GoToVan, 2020; Becker, 2020)

4.3.3.2. Mandatory Vaccination

Similar to the responses to restrictions on people's movements and gatherings, the introduction of mandatory vaccinations has also been an extremely controversial topic, leading to public protests in various countries. For example, Austrian protesters rebelled against it, expressing that it takes away their power of personal choice (Bell, 2022). The Austrian government suspended the law in 2022, with the Minister stating that it is encroachment of people's fundamental rights, and that the mandate

could no longer be justified (BBC News, 2022). In England, The Health and Social Care Act 2008 Amendment (Department of Health & Social Care, 2021) which required health and social care workers to be vaccinated against COVID-19 was met with a lot of criticism from various authorities (House of Lords). The government faced pressure to scrap the mandate, as they argued that it would lead to a staffing crisis (Rodger & Blackshaw, 2022). In addition, as the Omicron variant became dominant in early 2022, it became apparent that the vaccination of healthcare workers would no longer protect patients from infection, which was the rationale for mandatory vaccination of healthcare workers in the first place. As a result, regulations started being lifted from March 2022 in England (Department of Health & Social Care, 2021).

Countries around Europe also enforced measures which allowed only people vaccinated against COVID-19 or those who produced a recent negative PCR test entry into public spaces such as restaurants and pubs. Unvaccinated citizens were therefore banned from using leisure facilities such as entering bars and cinemas, attending sports events, or taking domestic flights. Thousands of protesters in European countries have opposed the use of vaccination certificates and other requirements regarding vaccination, especially as these were not equally applied everywhere due to the economic impacts of these measures and their threats on the viability of businesses such as restaurants and leisure facilities (Bardosh et al., 2022; Vergallo et al., 2022). In addition, while places like restaurants were the primary targets, there was no concrete evidence to prove that these places were a hot spot for transmission. As such, inconsistent measures without concrete evidence on which these decisions were based made them incomprehensible, and fuelled opposition and lack of trust from the population, as well as from the managers of these facilities to whom the economic impacts of the measures taken were highly visible.

4.3.3.3. Surveillance

Surveillance systems such as contact tracing apps and drones have important legal implications, especially concerning privacy and data protection. As already elaborated in section 4.3.1, various governments were criticised for not adhering to data protection regulations during COVID-19. In addition, the use of surveillance systems has been associated with acts of racism, discrimination, and police violence, which have led to further oppressions of marginalised groups (Bailey et al., 2021; Yearby, 2021). These have prompted negative reactions from the public, including protests against racial injustice and police brutality (Bailey et al., 2021; Lacoella et al., 2021; Krieger, 2020).

4.3.4. Government support schemes

During the COVID-19 pandemic, several government schemes were rolled out to provide discretionary financial support to various groups of people e.g., the Pandemic Unemployment Payment for Irish employees and self-employed people who lost all their employment due to COVID-19; the Coronavirus job retention scheme for workers in England; and the self-employment income support scheme for self-employed workers in the UK. To ensure compliance with human rights laws, it is crucial for governments to be transparent in justifying the decision-making processes behind these measures, including how they balanced competing interests and the evidence on which their decisions were based.

Key messages on legal issues:

The intent of pandemic response measures is usually clear from a public health perspective. However, policy makers also have a duty to carefully consider the effects that these measures could have on the public. If such mandates threaten to undermine the public's confidence and trust (for instance by a lack of evidence supporting them and by the major impact they may have on the economy and/or well-being), they could affect both compliance, and adherence to other important public health measures (Shetty, 2010). It is also important to recognise how such mandates may create additional barriers or inequities for some populations in society, making it more difficult for them to access jobs and other essential services (Bajos et al., 2021; Bardosh et al., 2022; Baylis & Kofler, 2021).

Various guidance documents and resources exist to address some of the legal issues identified in this review. Examples of these include the International Health Regulations (IHR) which provide an overarching legal framework that defines countries' rights and obligations in handling pandemic events (WHO); EDPB guidelines and Directive 2002/58/EC (European Parliament, 2002) which regulate the use of location data and contact tracing tools; and the EU Decision 1082/2013 (Guglielmetti, 2016) which provides rules on epidemiological surveillance, monitoring and early warning in pandemic preparedness. However, some of these legislations have no enforcement mechanisms (Speakman et al., 2017), while others have no formal sanctions or penalties associated with non-compliance (Wilson et al., 2020).

National legislations are a necessary step towards ensuring compliance during pandemics and are the strongest form of national commitment as they provide a clear image of actions that need to be implemented. There is therefore a need to ensure that current legislations clearly outline how ethical and legal issues associated with pandemic response measures can be addressed.

4.4. Social issues in pandemic preparedness & response

There is broad consensus that social determinants play a significant role in the development of diseases and are an important contributor to health inequalities. Findings from previous pandemics suggest that social determinants of infection risk and disease severity contribute to aggravated social inequalities in health, and thus widen the health gap (Burström & Tao, 2020; Lowcock et al., 2012). However, these findings are rarely acknowledged in the planning and implementation of pandemic response measures (Hoven et al., 2022). Identifying vulnerable groups and populations at risk is crucial for reducing the social gradient in health during a pandemic.

4.4.1. Defining Vulnerability

Vulnerable populations are individuals who are much more at risk than the rest of the population to the consequences of public health measures that have been imposed to control the spread of pandemics, due to their living conditions (Sokat & Altay, 2021). This increased risk may exacerbate their already challenging social and economic life situations. Examples of vulnerable persons as defined by the (ECDC, 2022) and (European Commission, 2021) include minors, disabled people, the elderly, pregnant women, people on low incomes, ethnic minorities, victims of human trafficking, persons with serious illnesses, persons with mental disorders, persons in long-term care facilities and persons who have been subjected to torture, rape or other forms of physical, psychological or sexual

violence, such as female genital mutilation. Healthcare workers are also an important vulnerable group during health emergencies, due to the huge workload they have to bear, the high levels of risks they are exposed to, and the resulting implications from these (Billings et al., 2021; Smith, 2020).

The British Red Cross (BRC) classified vulnerability during the COVID-19 pandemic into three categories, as (i) vulnerability in terms of pre-existing physical health status, (ii) social vulnerability to disease and (iii) communication vulnerability (Thomas & Gordon, 2021) (see figure 4).

As shown in the figure, vulnerability in terms of pre-existing physical health status includes vulnerabilities relating to clinical, human and wellbeing needs, such as pre-existing medical conditions, mental health status, and health inequalities.

Social vulnerability considers how social and economic factors, including occupation, material and social deprivation, family situation, legal status and race/ethnicity contribute to health risks and poor health outcomes in vulnerable groups.

Communication vulnerability relates to factors that create difficulties in expressing one's needs, or in obtaining, understanding, or using information relevant to public health emergencies. Examples of these include literacy levels, language barriers, communication materials and methods, religious beliefs, and sociocultural influences on health perceptions.

Pandemic communication is discussed in more detail in WP5 of the PANDEM-2 project. The sections on communication vulnerability highlight key communication considerations for the vulnerable groups discussed in this report. An important feature of this classification system is that it recognises multiple levels of vulnerability within each category, which enables vulnerability to be understood as a result of different and interdependent factors and processes that create multiple dimensions of marginalisation. The identities of vulnerable groups are very often homogenised, without regard for the intersecting traits and factors that make some groups more vulnerable to the effects of a pandemic than others (Kuran et al., 2020). Recognising intersectionality paints a more nuanced picture of vulnerabilities and vulnerable groups, which is useful for identifying priority groups during pandemic preparedness planning (Kuran et al., 2020).

Vulnerability in terms of pre-existing physical health status

Combination of:

- Clinical vulnerability (e.g., people over 70 or people with underlying health conditions)

&

- Human & wellbeing needs vulnerability (e.g., people with dementia, drug-related hospital admissions or serious mental illness)

Social vulnerability to disease

Combination of:

- Economic/financial vulnerability (e.g., adults receiving social care benefit, people receiving employment and support allowance)

&

- Social vulnerability (e.g., people with poor access to GP surgeries, supermarkets, housing or digital platforms

Communication vulnerability

- Vulnerabilities relating to groups or individuals who are unable to access, understand or react to communication about the COVID-19 pandemic

Figure 4: British Red Cross COVID-19 vulnerability index

4.4.2. Impact of pandemics on vulnerable groups and considerations for pandemic preparedness

Using examples from COVID-19 and other public health emergencies, the impacts of pandemics and pandemic responses on vulnerable groups are discussed below, following the BRC categories of vulnerability. This review will focus on four vulnerable groups that were identified as priority in the literature. These are persons of migrant origin, older adults, healthcare workers and people with disabilities. Important considerations for future pandemic preparedness planning are also highlighted, to minimise further risks to these vulnerable populations.

4.4.2.1. Persons of migrant origin

(i) Vulnerability in terms of pre-existing physical health status

Migrants were identified as high-risk groups for COVID-19, as they were disproportionately represented among cases (Hayward et al., 2021). They were also shown to have significantly higher risks of hospitalisation and mortality compared to their peers in the general population (Coyer et al., 2021; Drefahl et al., 2020; Indseth et al., 2021). There are several factors associated with the disproportionate risk among migrants including biological and genetic susceptibilities, high-risk occupations, overcrowded accommodation, barriers to access to information concerning preventive measures (e.g., due to the language barriers), difficulties in accessing treatment and public health services, and reduced entitlement (Hayward et al., 2021). Migrants living in precarious situations such as refugees in camps are also particularly vulnerable due to existing illnesses, prevailing malnutrition, or poor health in general (Hargreaves et al., 2020; Iacobucci, 2020). In addition, they often have limited access to water, sanitation systems and health facilities (Hargreaves et al., 2020).

The implementation of certain pandemic measures may also exacerbate the risks of pandemics for migrant groups. For example, restricting people's movements often leads to a deterioration of healthy lifestyle factors such as nutrition, physical activity, sleep, and increased alcohol consumption. These factors are known to increase the risks of underlying medical conditions including cardiovascular disease, type-2 diabetes, and obesity, which are highly prevalent among migrant groups (Hayward et al., 2021; Wernly et al., 2020). Findings from France and Sweden showed examples of these – asylum seekers and undocumented migrants in France were shown to have a high prevalence of diabetes, hypertension, and obesity during COVID-19 (Gosselin et al., 2020), while 65% of refugees in Sweden were reported to be either overweight or obese compared to 50% in the general population (Elisabeth et al., 2020). These underlying medical conditions were associated with worse COVID-19 outcomes (Hargreaves et al., 2020; Hayward et al., 2021; Palmer et al., 2020; Pécout et al., 2021). Hospital visits for management of comorbidities were also identified as a further risk of exposure to COVID-19 (Hayward et al., 2021). Factors like nutrition and physical activity are therefore important to consider when planning restrictions in the general population, as they may further widen gaps in health outcomes for some groups. Studies have also documented disproportionately worse mental health outcomes in migrants during pandemics, mostly related to social and economic factors including migrant-related stressors, stigma, and discrimination (Chander et al., 2021; Czeisler et al., 2020; Spiritus-Beerden et al., 2021). These are discussed in further detail under social vulnerability. Mental health outcomes have been worse for asylum seekers and refugees, who already suffer from increased discrimination and elevated stress regarding material and medical daily needs (Spiritus-Beerden et al., 2021).

While there is evidence identifying causes of increased risks of infection during pandemics and poor outcomes in migrant populations, the data is fragmented and not comparable across countries. For example, unlike the popular finding that migrants are at increased risk, some countries (e.g., Italy) reported fewer adverse impacts in migrant groups compared to the general population (OECD, 2020). These discrepancies were attributed to differences in demographic structures and the different ways in which the pandemic hit across countries. Some countries such as the UK also do not report data on mortality for immigrants (this is available for ethnic minorities, but not by migrant status) (OECD, 2020). Hayward et al. (2021) also reported that while comorbidities were recognised as a risk for migrants and refugees, they were poorly documented during the COVID-19 pandemic. These gaps are critical for pandemic preparedness planning, as the lack of comparable data challenges the collection and monitoring of data that is truly representative of the population, which impedes good policy development. The WHO emphasises the need for investments to improve the quality, relevance, and completeness of health data on refugees and migrants (WHO, 2022b).

(ii) Social vulnerability to disease

Ethnic minority groups are more likely to face life situations that increase their risks of adverse health outcomes compared to the general population. Examples of these include high rates of unemployment and job losses, working under precarious circumstances (Baptist et al., 2020) et al., 2020), experiencing food and housing insecurity, living in deprived neighbourhoods, living on low incomes, or living in confined spaces with large families (Burton-Jeangros et al., 2020). Access to healthcare, including difficulties in accessing medication and public health services, also appear to be common challenges experienced by migrant groups, as reported during previous health emergencies

(Baptist et al., 2020; Schoch-Spana et al., 2010). Other studies have reported fear of stigmatisation as a common worry among ethnic minority groups, due to pandemic diseases being socially associated with these groups (Eichelberger, 2007; McCauley et al., 2013; Pang, 2021). For example, SARS with Asian populations, H1N1 with Hispanic populations, and Ebola with African populations (Yashadhana et al., 2022). This is often fuelled by the abundance of incorrect information or 'harmful' advice and fear-based messages being disseminated relating to ethnic minorities via traditional and social media (e.g., Cheah et al., 2020; Yang et al., 2020). This stigmatisation often manifests as abuse (verbal and physical), avoidance or hyper-surveillance (Pang, 2021). Consequently, some migrants resort to countering this stigma by displaying avoidance behaviours such as refraining from contact with people, spaces and objects associated with their cultural backgrounds (Zheng et al., 2005). Such actions and experiences play a heavy toll on the mental wellbeing of these populations. For instance, in the UK, there were increased reports of abuse, self-harm and suicidal thoughts among ethnic minority groups during COVID-19, compared to the white population (Lob et al., 2020). The impacts are even worse for some migrant groups who have limited state protections, such as asylum seekers, refugees, and undocumented migrants.

The socioeconomic limitations faced by migrant groups also highlight their increased vulnerability to the economic consequences of pandemic response measures like lockdowns, social distancing, and business closures. For instance, living in low-income households may influence people to go against public health stay-at-home orders, as a necessity to provide for their families. It should therefore be recognised that poverty places significant demands on people, which could limit their ability to comply with certain restrictions. Moreover, there is ample evidence to suggest that in the aftermath of a disaster, economic inequality increases (Jetten et al., 2017). Considerations should be made to empower people – for instance, by providing alternative solutions such as temporary financial assistance, to allow them to stay at home when required.

Other measures that were implemented in response to the COVID-19 pandemic such as school closures and distance learning for children also created additional challenges for migrant groups. For example, low-income parents may not have access to a computer or internet connection at home, or migrant parents may not have the resources to help their children with their homework (e.g., due to language barriers). The physical and psychosocial needs of migrant groups should be considered during pandemic preparedness planning, and this should include identifying different needs within these groups. If not properly addressed, it is likely that these issues will become even more dominant and difficult to address in subsequent pandemics. Representation of ethnic minorities in the planning and implementation of healthcare strategies are also key to identifying and addressing the specific concerns of ethnic minorities at policy level.

(iii) Communication vulnerability

The diverse needs and circumstances of target communities should be at the centre of health messages, especially those involving behaviour change. Culturally appropriate health information and messaging is key to pandemic preparedness and response. To be successful, generic approaches should be avoided. Rather, communication should be culturally sensitive and integrate the needs of target audiences. Surveys aimed specifically at migrants and minority populations could help highlight communication needs and gaps, to better inform pandemic preparedness and response interventions.

Messages should be tailored to the needs of these groups to enhance understanding, e.g., by translating information into different languages, providing interpreters where required, and engaging target communities, and collaborating with community leaders in identifying language that retains the meaning of core messages and considers their cultural context (Behaviours, 2020). For example, words such as shielding and self-isolation do not retain the same meaning and cultural context when translated to other languages (SPI-B, 2020). Communication methods should also be tailored to reflect socio-cultural influences and drivers of behaviour, which may be different from those of non-migrant or majority populations. Digitalization and virtual consultations during COVID-19 caused increased inequalities in access to healthcare for many migrants and refugees due to poor digital literacy and access to technology (Arya et al., 2021; Knights et al., 2021). Actively involving migrant communities in all stages of the creation and distribution of health messages can serve to encourage widespread participation in prevention programs (e.g., vaccination) and empower migrant and minority healthcare professionals within communities (Crawshaw et al., 2021).

Trust is an important factor in communication with migrants, as these groups may be less willing to trust government communications on pandemic measures due to historical issues and contemporary perceptions of institutional racism. Health messages are more likely to be accepted when presented by people known and trusted within migrant communities (Koval et al., 2021). These include faith groups, community leaders and lay health educators. Learning from the Ebola epidemic, using community leaders as advocates was instrumental to promoting key public health guidance and facilitating trust in vaccine campaigns (Dada et al., 2019). Partnerships between culturally and linguistically diverse leaders, communities and the government are also shown to be critical for effective health communication during pandemics (Santibañez et al., 2015; Wild et al., 2021). These strategies will require funding for relevant community stakeholder groups and training to understand local community needs and deliver consistent and relevant messages.

Previous pandemics also exposed cases of misinformation, e.g., through social media (Gabarron et al., 2021; Larson, 2018; Rocha et al., 2021), which undoubtedly contributed to further marginalisation of minority groups. Nonetheless, social media has far-reaching capacities and should be exploited as an information gathering tool, as well as a message dissemination tool within minority groups, as well as the wider population. Platforms like Facebook, Twitter, Instagram, YouTube, and online blogs were found to be major sources of COVID-19 information for many migrants (Goldsmith et al., 2022). Misconception concerns can be addressed through effective communication strategies.

4.4.2.2. Older Adults

(i) Vulnerability in terms of pre-existing physical health status

Older age during the COVID-19 pandemic was associated with greater risks of hospitalisation (Soares et al., 2020), disease severity (Fang et al., 2020; Zheng et al., 2020) and deaths (Bhaskaran et al., 2021; Dessie & Zewotir, 2021). There are many potential explanations as to why this group was one of the hardest hit by the pandemic. Older age predisposes adults to a host of underlying health conditions such as chronic disease, hypertension, cardiovascular disease, and respiratory system diseases, all of which were strongly associated with an increased severity of COVID-19 (Mueller et al., 2020). Being resident in a nursing home was also shown to increase their exposure and vulnerability to the disease

(Bernardi et al., 2021). In addition, measures such as social distancing were impractical or nearly impossible for people with age-related neurodegenerative disorders such as dementia or Alzheimer's disease, or those with severely reduced mobility (Ryoo et al., 2020). This made prevention and treatment even more complicated for these groups.

Due to their identification as high-risk populations, older adults experienced some of the most prolonged and extreme health intervention strategies during COVID-19. While the rationale for this approach was clear, these interventions took a severe psychological toll on the elderly population, resulting in increased levels of anxiety, depression, loneliness, and other adverse mental health outcomes (Armitage & Nellums, 2020; Bavel et al., 2020). The resulting implications on the healthcare system include increased mortality, increased need for social care, increased healthcare costs and a further widening of age-related inequality gaps in healthcare. Pandemic preparedness plans should therefore address the devastating impacts on older persons, both during the crisis and recovery phases.

(ii) Social vulnerability

Older adults faced high levels of isolation during the COVID-19 pandemic, which significantly affected their quality of life. The changes to their daily lives not only affected them as individuals, but also as members of family units. Many older adults rely on relatives and loved ones for social support, and to maintain their health, well-being, and safety (Hado & Friss Feinberg, 2020). However, measures such as lockdowns and social distancing deprived many older adults from this social support and prevented them from properly mourning the death of their loved ones. Social disconnection in elderly populations is associated with adverse biological and mental health outcomes (Wu, 2020) and can worsen pre-existing neurodegenerative disorders such as Alzheimer's disease (Plagg et al., 2020). While age is its own inequality, the physical and mental effects on older people from more disadvantaged socioeconomic backgrounds are more severe. For example, a survey by Age UK (2020) found that older people whose personal circumstances were physically or financially limited e.g., not having a garden or space or experiencing financial difficulties on top of the pandemic, made their experience of lockdown much more challenging. This, compounded with the inability to take part in or benefit from activities or services they previously had access to, contributed to increased levels of anxiety and poor mental health. Pandemic response plans that include psychosocial support for older adults may prevent aggravated mental health conditions of residents in nursing homes (Kaelen et al., 2021). It would therefore be helpful for solutions to visitation restrictions to be considered, to ensure that older adults can maintain their social networks and benefit from social support during such health emergencies.

(iii) Communication vulnerability

Due to restrictions on in-person contact during the COVID-19 pandemic, the main strategy used to reduce social isolation and facilitate communication between older adults and their families was through information and communication technology (ICT) and family support groups (Veiga-Seijo et al., 2022). Findings from a 2021 study showed that the more messages older adults read on a web-based support platform, the less depressed they felt at a one-year follow up (Hwang et al., 2021). This shows potential benefits of these technologies for combatting depressive symptoms. Compared to older adults who used the internet daily to communicate with friends and family, those who used the

internet less frequently reported increased loneliness, lower life satisfaction, and more depressive symptoms (Hajek & König, 2022). Such findings highlight the importance of technology to bridge the communication barrier.

However, a major barrier to the implementation of online resources for older adults is their hesitancy to uptake new technologies (Wilson et al., 2021). Some reasons for this hesitancy include poor digital literacy, low income, diminished interest in learning how to use new technology, difficulty in using technological devices due to poor eyesight and hearing, and safety or privacy concerns (Moore & Hancock, 2020; Gorenko et al., 2021). Another consideration is the accessibility of these devices, which may be limited in some settings such as long-term care facilities. As such, while technology may have helped bridge some gaps in healthcare communication, communication capabilities of older adults still need to be addressed. The successful adoption of social technologies for pandemic situations will need to first tackle elderly adult mindset around the use of technology and address poor digital literacy around online safety (Rodrigues et al., 2022). This will require support from key stakeholders such as technology companies and community-based organisations. The cost of such devices should be considered, e.g., by providing access to second-hand refurbished, rented, or loaned devices, which may help ease this burden and support uptake. Communication strategies for older adults also need to be diverse and cover many communication channels as certain populations, such as older people, are more informed by TV than internet (Skarpa & Garoufallou, 2021).

4.4.2.3. Healthcare workers

(i) Vulnerability in terms of pre-existing physical health status

The clinical vulnerability of health professionals during pandemics comes from the high level of risks they are exposed to, owing to their commitment to provide care to patients. Unlike in many other fields where workers were able to work from home during the COVID-19 pandemic, health care workers were constantly in harm's way, as they were required to be present physically to do their work. As such, they faced an increased risk of infection and spreading the virus to others (Nguyen et al., 2020). The risk goes beyond the impact to themselves, as there are implications on the health of people with whom they live and meet outside of work.

In addition to the physical threat of pandemic diseases on frontline healthcare workers, negative mental health impacts and their long-lasting effects are also widely documented. Studies from the COVID-19 pandemic showed many healthcare workers reporting a decline in their mental well-being due to anxiety relating to fear of infection and disease transmission, emotional exhaustion from navigating difficult working conditions, directly witnessing the suffering and death of patients, guilt, isolation from family and poor support (Creese et al., 2021; Vanhaecht et al., 2021). Reports of increased symptoms of anxiety disorders, post-traumatic stress disorder (PTSD), depression and burnout were also prevalent. In Italy and Spain for example, healthcare workers who worked in COVID-19 wards reported higher levels of anxiety, insomnia, PTSD, anger, and burnout than those in non-COVID wards (Di Mattei et al., 2021; Luceño-Moreno et al., 2020). General practitioners in Latvia frequently reported symptoms of depression and anxiety and working more than 48 hours during the week was associated with a higher risk of depression (Valaine et al., 2021). In France, nurses perceived their frontline position as a risk to their safety and wellbeing (Chandler-Jeanville et al., 2021). These

factors challenge the ability of healthcare workers to provide care to patients, as there are increased risks of medical errors and poor clinical decision-making (Leo et al., 2021; Salyers et al., 2017).

Healthcare workers have also faced extreme moral and ethical dilemmas relating to patient care, which made them vulnerable to experiencing moral injuries. Moral injury is defined as profound psychological distress resulting from actions (or the lack of them), which violate one's moral or ethical code (Litz et al., 2009). Examples of these include doing something one felt should not have done (such as taking a patient off potentially life-saving treatment to make it available for another patient); failing to do something one felt should have been done (such as failing to properly screen a patient, resulting in other vulnerable patients being exposed to COVID-19); or feeling betrayed by other people's actions or inactions (such as decisions on resource allocation, patients infected after blatantly ignoring recommended protective measures and wilfully disregarding them). Although not specifically classed as mental illness, morally injurious events have been linked to feelings of shame, guilt, or disgust, which can in turn contribute to the development of mental health problems, and adversely affect a person's ability to function effectively (Williamson et al., 2018). Implementing an independent triage committee to take charge of deciding allocation and removal of life-saving resources and communicating these decisions to patients' families was suggested as a preventative measure to protect healthcare workers from potential moral injury (Truog et al., 2020). The benefit of this approach is that it shares the burden of making difficult ethical and moral decisions among all members of the committee. It also removes the weight of making these difficult ethical and moral choices from the clinician administering patient care, allowing them to focus on their role (Truog et al., 2020).

(ii) Social vulnerability

Healthcare workers face multiple work-related challenges during health emergencies, including increased workload, a general lack of public and organisational recognition, and feelings of disempowerment (May et al., 2021). In addition, they are placed in a sensitive position where their commitment to the duty to treat may conflict with concerns about protecting themselves and their families (McConnell, 2020). The increased mental burdens among healthcare personnel have been associated with a high tendency to take sick leave and intentions to change profession (Röthke et al., 2021). Some healthcare workers also faced financial instability, due to earning low wages and having limited savings to fall back on when they were unable to continue working as a result of getting infected (Almeida et al., 2020).

Several factors from COVID-19 response efforts contributed to healthcare workers experiencing mental distress. For instance, in situations where frontline healthcare workers needed support from leaders, many felt they received the opposite, which perpetuated feelings of pain, frustration, and anger (Billings et al., 2021). Secondly, the limitation of resources such as PPE and ventilators during COVID-19 caused healthcare workers significant moral distress, and negatively impacted their feelings of personal safety (Nelson et al., 2022). While acknowledging that leaders themselves faced significant pressures which may have influenced their approaches to employee mental wellbeing, it is important for leaders to support healthcare workers' ability to share concerns and questions without being treated as the problem (Giusino et al., 2022).

The above findings highlight the need for social support for healthcare professionals. A review of the psychological impact of previous health emergencies on healthcare workers and first responders identified social and occupational factors that influence psychological outcomes, including training and preparedness, extent of traumatic exposure, social support, job demands, perceptions of safety or risk, and impact on personal life (Brooks et al., 2017). These factors should be taken into consideration during pandemic preparedness, to ensure that healthcare workers are adequately supported. (Shanafelt et al., 2020) also identified five key requests from healthcare workers, reflecting their concerns during the COVID-19 response. These were: 'hear me', 'protect me', 'prepare me', 'support me', and 'care for me'. Addressing these issues during future pandemic preparedness plans would facilitate personal protective factors (e.g., sense of control) and resilience among healthcare workers (Uphoff et al., 2021). Other mechanisms to help healthcare workers feel protected in the workplace include staff feedback sessions, which would allow them to contribute to decision-making in the workplace. It would also be useful to develop a toolkit with guidelines, protocols and resources on biosafety and biosecurity for first responders, clinical staff, and laboratory personnel during cross-border responses. In addition, it would be helpful for front-line staff to be made aware of the potential of encountering morally injurious events in their role when handling healthcare emergencies. Discussing these issues in advance could help enhance psychological preparedness.

(iii) Communication vulnerability

As witnessed during the COVID-19 pandemic, policies and practices change often. A recent study suggests that 35% of healthcare workers felt that their organisation was either not effective or only slightly effective at communicating system-based changes (Nelson et al., 2022). Lack of clear communication and inconsistent enforcement of policies, rules and practices by organisational leaders can breed uncertainty, which can lead to fear and anxiety, and potentially, a loss of trust in leadership. Inconsistent enforcement of policies, rules and practices by organisational leaders can also increase the potential for HCWs experiencing anxiety and stress (Nelson et al., 2022; Uphoff et al., 2021). Thus, clear and frequent communication is key to helping healthcare workers feel protected and in control. Healthcare workers can also offer perspective as both individuals working in precarious conditions, and as individuals witnessing the effects of the pandemic on a population. Communication with healthcare workers therefore needs to better incorporate their feedback. In fact, prevention strategies could focus more intensively on the most at-risk groups, specifically young nurses who work in at-risk services, mainly in emergency and internal medicine (Rodríguez de Limia Ramírez et al., 2021). In planning for future public health crises of COVID-19 scale, healthcare leaders should be sensitive to the fragility of trust in the workplace and be equipped to address it. Breaches of trust by leaders, whether intentional or unintentional, can erode employee satisfaction, work engagement, and attrition.

Reflections from the USA by (Salmon et al., 2021) highlight how effective communication will require rapid and rigorous science to promptly differentiate between adverse events following immunisation. Health care providers will need support to process relevant information and effectively integrate it into discussions with their patients to support their decision making. Hospitals should implement policies ensuring that all staff receive information, equipment, and support necessary to battle the current crisis and protect essential workers (Maurer et al., 2020).

4.4.2.4. People with disabilities

(i) Vulnerability in terms of pre-existing physical health status

Disability is an umbrella term which can include physical, mental, or intellectual impairments that substantially limit major life activities (Altman, 2014). What is less clear about people with disabilities is exactly how their health was affected due to pandemic-related restrictions. Shakespeare et al. (2021) describe the situation from COVID-19 as a 'triple jeopardy', as people with disabilities were differentially affected due to three factors: the increased risk of poor outcomes from the disease itself, reduced access to routine health care and rehabilitation, and the adverse social impacts from pandemic mitigation measures. Taking the UK for example, data published by the Office for National Statistics in 2020 showed that disabled people accounted for 59% of COVID-19 deaths (Putz & Ainslie, 2020). People with severe mental illness and learning disabilities in the UK had high risks of hospital admissions and deaths due to COVID-19 (Beaney et al., 2022; Williamson et al., 2021); and they had higher rates of depression compared to non-disabled people (Williams, 2021).

There were also reports of increased anxiety, depressive symptoms, and generally poor mental wellbeing in adults with autism in various countries including Spain, Belgium, the Netherlands, and Australia (Hedley et al., 2021; Lugo-Marín et al., 2021; Oomen et al., 2021). These were often in relation to the lockdown and decreased social interaction. Another effect of the lockdown was a decrease in their physical activity levels (De Boer et al., 2021; Rogers et al., 2020); which, as earlier explained, contributes to an increased risk of underlying health conditions such as cardiovascular disease, obesity, and hypertension (Palmer et al., 2020; Pécout et al., 2021). People with severe mental illness also had a heightened risk of relapse due to their high susceptibility to stress under lockdown measures, and an overall reduced ability to cope with stress in disaster situations compared to the general population (Jesus et al., 2021). In addition, many disabled persons experienced a lack of access to specialist facilities, therapies, and equipment, which had negative impacts on their behaviour, mood, fitness, and learning (Theis et al., 2021).

People with disabilities may be at greater risk of developing more severe cases of pandemic diseases if they become infected, partly due to their already existing health conditions and compromised immune system functions. It is important to plan for the continuation of disability services during pandemic preparedness, to ensure that people with disabilities can always access the healthcare services and public health information they require. More on communication with people with disabilities during pandemics is discussed under communication vulnerability below.

(ii) Social vulnerability

According to a report by the United Nations (2020), people with disabilities experienced widespread discrimination and exclusion during COVID-19, which exacerbated existing inequalities resulting in them dying at higher rates, being pushed further into poverty, and excluded from pandemic response measures. They identified numerous barriers to accessing health care that people with disabilities experienced during the pandemic, including inaccessible information, transport and health care facilities, lack of trained staff, extra costs, lack of support services or rules that prevent those seeking health care to be accompanied by a personal assistant or a family member (United Nations, 2020).

There were also discriminatory medical protocols that resulted in people with disabilities infected with COVID-19 being denied lifesaving treatment. For example, clinical frailty scales that inform triage policy often classified people who were unable to do everyday tasks like cooking and dressing independently as 'frail' (Rockwood & Theou, 2020). Such classifications would deny life-saving treatment to persons with other forms of disability, such as intellectual impairments and long-term stable conditions like cerebral palsy. People with disabilities have also had blanket 'Do Not Attempt Resuscitation' notices imposed on them without their consent (Glasper, 2021). Various authors have attributed these discriminatory medical protocols to ableist assumptions about the overall health of people with disabilities, and negative assumptions about their quality of life (Andrews et al., 2021; Mukherjee et al., 2022; Panocchia et al., 2021).

There have been reports on other challenges such as reduced access to food, essential supplies, health and social care, and reduced access to education for children and young people with special educational needs and disabilities (Friedman, 2021; Karpur et al., 2021; Ofsted, 2021) 2021). The economic impact of COVID-19 was also shown to have a disproportionate effect on disabled people, with pay gaps being identified (Friedman, 2022). In addition, many people with disabilities have experienced an increase in their expenses as the costs of regular medications, food and safe transport have increased, meanwhile their income levels decreased (Friedman, 2022). The intersections of disability with poverty mean that people with disabilities often live in precarious situations which may make it more likely for them to contract the disease and become seriously ill, or where it is difficult for them to maintain practices like social distancing and personal hygiene. Another major challenge for this group is the loss of social support systems and worries about losing their social skills due to reduced social interactions and loss of regular care services (Jesus et al., 2021; Oomen et al., 2021). In fact, those with a higher disability degree reported lower social function, decreased well-being, and an increase in risk behaviour. Enacting preventive measures such as social distancing was also difficult, due to additional support needs or people with disabilities being institutionalised (Oomen et al., 2021).

As declared by the UN, there is a need to challenge and remove assumptions that create barriers for people with disabilities in accessing health care (Hendriks, 2007). Provisions should also be made to raise awareness and provide training for healthcare professionals on the rights and diversity of people with disabilities.

(iii) Communication vulnerability

The ability to adequately care for and support the entire population during and following pandemics revolves around communication. When news of COVID-19 first emerged, it was typically presented as a disease that affected the elderly and those with pre-existing medical conditions. By this definition, young and 'healthy' people were considered to be at less risk. The category of underlying health conditions was used prominently, with little reference to disability. This is problematic as there are many people with disabilities who may not have 'underlying health conditions', but risk losing rights and support if their disability is overlooked (e.g., people who are deaf and need accessible communication) (The Health Foundation, 2021). Secondly, for people with disabilities who do have underlying health conditions, there are multiple factors that heighten their risk of pandemic diseases. In England and Wales for example, two-thirds of people who died from COVID-19 lived with disability, and it is estimated that people with disabilities had up to 11 times higher odds of dying from COVID-

19 in the first two months of the pandemic compared to the non-disabled (ONS, 2022). There is a need for greater visibility and understanding of disability-related pandemic risk factors, as well as public health guidelines specific to people with disabilities (Desroches et al., 2022; Rotarou et al., 2021).

Scully (2020) described perspectives and practices that exclude, discriminate against, and oppress people with disabilities during COVID-19, which they referred to as 'disablism'. This is exemplified through a lack of accessible information for people with disabilities, whereas communication is crucial during a pandemic. For example, not all states provided sign language interpretation during COVID-19 government briefings (Rotarou et al., 2021). In addition, laws and rules change rapidly during pandemics and keeping up with these changes is difficult for everyone, but even more so for people with learning disabilities and other cognitive impairments.

Measures like social distancing and good hygiene practices are also particularly challenging for people with disabilities. The deaf-blind community for instance, and other people who require assistance to go about their daily lives cannot communicate without touch, as they rely on this to navigate public spaces including braille signs and shared surfaces such as handrails, door handles and handrails on public transport (Goggin & Ellis, 2020; Jesus et al., 2021). For people with intellectual disabilities, social distancing is difficult to understand and not always an option. Self-isolation is also impossible if one relies on carers in daily life (Kuper et al., 2020). The disadvantages experienced by people with disability due to disabling environments, the multiple intersectionalities of disability, and the materialities of their impairments, must therefore be compensated for with additional support, resources and accessible information. While various measures have been taken to include the communication needs of this population, there is still a long way to go before such practices become standard and seamlessly integrated into public emergency responses, and indeed, routine communication.

Key messages on social issues:

Previous pandemics have shone a light on existing inequalities, especially concerning vulnerable groups. They have also shown how national and international pandemic preparedness plans almost completely disregard social determinants as drivers of disease occurrence and progression. The practical consequences are far-reaching, with many countries lacking social-epidemiological systems that help in the early identification of vulnerable groups. Taking social determinants into account in pandemic preparedness plans will lead to better planning, both in the provision of pandemic-relevant services and resources, and in risk communication.

Important considerations that need to be made when addressing vulnerable populations include the need to: adjust communication materials for people with lower literacy levels or who do not speak the local language; use appropriate language to avoid stigma and discrimination; debunk misinformation and rumours; provide information in other languages to enable access for migrant groups and collaborate with organisations that translate materials for marginalised groups (Hyland-Wood et al., 2021; Maldonado et al., 2020).

The WHO in 2020 highlighted the importance of risk communication and community engagement (RCCE) during pandemic response, which should consist of two-way communication between health

authorities and at-risk populations (WHO, 2020b). RCCE for vulnerable persons needs to be clearly defined with the best existing information available and engage partner organisations at local, regional, and national levels. Coordination with various stakeholders including policymakers, influential social media leaders, local leaders, women and youth groups, religious and elders' groups, local and international NGOs, health practitioners and volunteers, is also instrumental to the dissemination of information during pandemics (WHO, 2020b). As elaborated in WP5 D5.1, it is important to listen to community concerns and to match communication methods and materials accordingly. RCCE must keep cultural diversity in mind and not funnel individuals into one category of vulnerability. It is also vital to keep in mind the potential for intersectionality of vulnerability during pandemics, as multiple vulnerabilities can expose individuals to additional risks of poor health.

4.5. Summary

This chapter has discussed important ethical, legal, and social considerations associated with pandemic preparedness and response, and highlighted important considerations for future pandemic preparedness planning, drawing on lessons from previous pandemics. It has also shown that some of the issues identified have cross-cutting implications, e.g., ethical and legal issues associated with privacy and data protection; ethical and social consequences of health and safety; social and legal implications of workers' rights, etc. These intersections (summarised in Figure 5 below) highlight the need for multi-disciplinary approaches in addressing these issues. Figure 5 further identifies factors that are central to decision-making when considering ELSI in pandemic preparedness and response, including value conflicts, transparency, trust, proportionality, and accountability. It also illustrates the interconnections between ELSI and decision-making frameworks, and their resulting consequences on the public as well as public responses to pandemic decisions. To be able to build back better and fairer following pandemics, it is important that these issues be fully understood and incorporated into guiding frameworks and policies. Lastly, the importance of cohesiveness in frameworks that guide decision-making when addressing ELSI in pandemic preparedness and response cannot be over-emphasised.

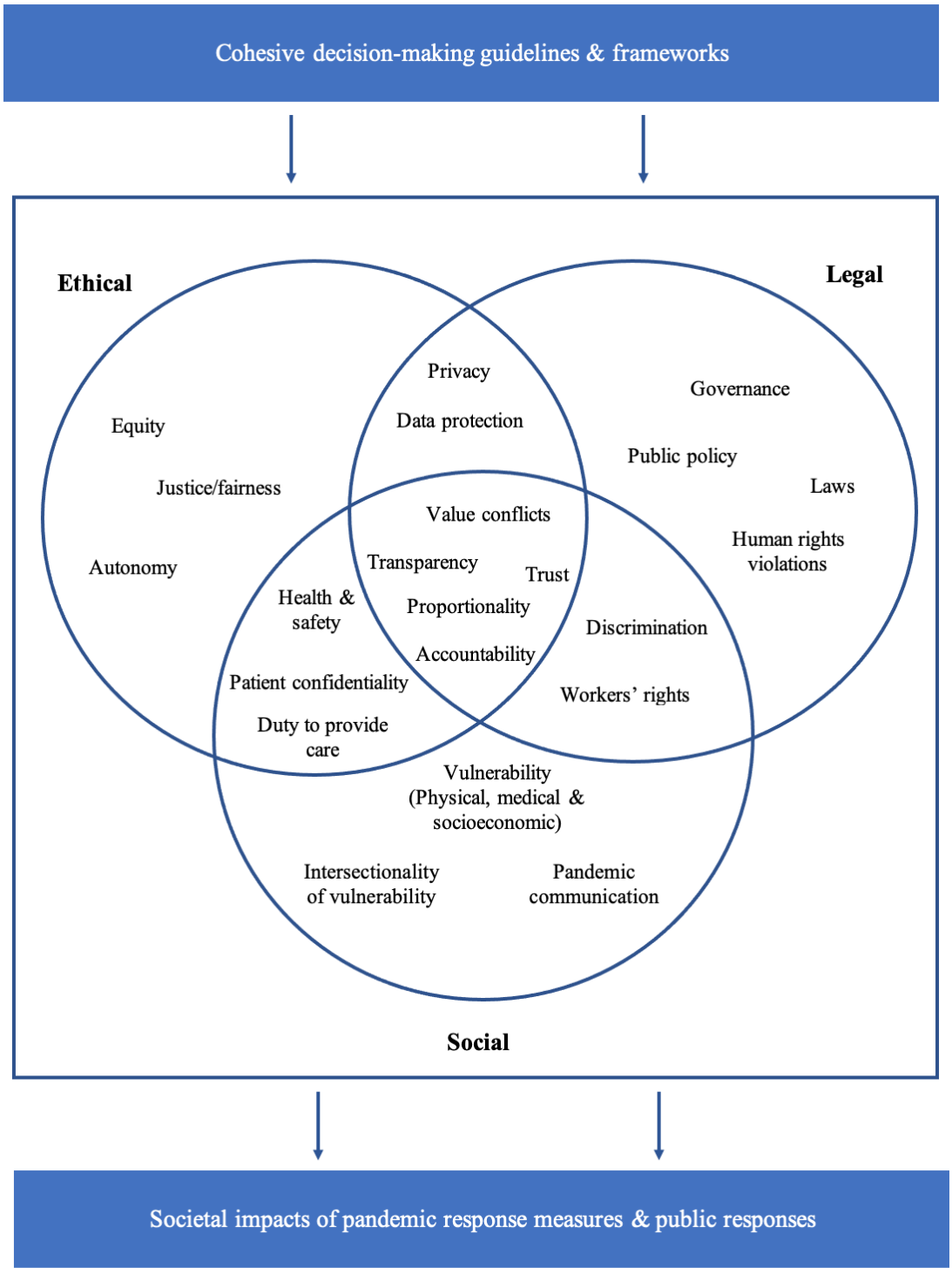


Figure 5: Interconnections between ELSI, guidance frameworks and public responses

5. Impact and conclusion

5.1. Recommendations for mitigating ELSI risks in pandemic preparedness and response

Ten recommendations were generated from this deliverable. These were grouped into five themes as shown in Box 1. Nine of the recommendations (all except recommendation 6) were discussed at the ELSI workshop, all of which were deemed relevant by workshop participants. One additional recommendation (recommendation 6) was proposed by members of the project team following the workshop. Several considerations were proposed regarding the feasibility and implementation of these recommendations, as well as implications for PANDEM-2. These are discussed below.

Box 1: Recommendations to mitigate ELSI in pandemic preparedness and response

Ethics framework

1. Develop an Ethics framework incorporating relevant ethical principles that need to be prioritised during pandemic preparedness planning and response

Pandemic communications and information

2. Messages should be consistent, clear, and understandable; and communication should be done using culturally appropriate methods, with accessible materials tailored to various social groups
3. Risk communication and community engagement needs to clearly define vulnerable persons, be two-way, and engage local, regional and national partner organisations (WHO, 2020b)
4. Coordination with policymakers, influential social media leaders, local leaders, women and youth groups, religious and elders' groups, local and international NGOs health experts and practitioners, volunteers, and people with experience of pandemic diseases is key in disseminating information to all (WHO, 2020b)
5. Misinformation should be addressed through media surveillance, feedback, emergency anthropology studies, and other social science tools (WHO, 2021c)
6. Educate communities about the complex realities of pandemics and good pandemic management, to enhance public understanding of pandemic decisions, and to promote receptivity and compliance with messages delivered by public health authorities

Legislations

7. Legal policies concerning digital contract tracing apps should make provisions to address ethical and legal concepts including privacy and data protection, and outline clear steps on what to do in case of data breaches
8. National legislations concerning emergency responses should be consistent with international health regulations, to establish comprehensive and appropriate response procedures

Evaluation of digital technologies and tools

9. IT systems and tools used for pandemic preparedness and response (such as predictive modelling tools, epidemic surveillance systems and contact tracing apps) need to be constantly evaluated, updated, and re-evaluated to ensure that they are effective and meet appropriate ethical and legal standards

Further research

10. Further research is required to inform the development and implementation of digital technologies and tools used for pandemic preparedness and response

I. Ethics framework

Recommendation 1: **Develop an Ethics framework incorporating relevant ethical principles that need to be prioritised during pandemic planning and response**

An appropriate agency, such as the European Centre for Disease Prevention and Control (ECDC), the European Health Emergency Preparedness and Response Authority (HERA) or the EU agency for Fundamental Rights (FRA) should develop a clear ethical framework incorporating relevant ethical principles that need to be prioritised during pandemic preparedness planning. This framework should serve as a foundation for pandemic preparedness and response, to enable congruity across decision makers in EU member states. It will also allow for a shared understanding of the decision-making process and optimise acceptance of decisions by health care workers and members of society.

The need for an ethical framework was previously identified in the *PANDEM D4.2* report, as well as others (O'Sullivan et al., 2022; Smith & Upshur, 2019; WHO, 2007). As of September 2022, when this report was completed, such a framework had not yet been developed for the EU. This recommendation therefore re-emphasises the need for this framework. Considerations relevant to this recommendation are summarised in Box 2 below.

Box 2: Considerations for recommendation on ethical framework

Public benefit vs individual rights

- The ethics framework should emphasise the benefit for public health vs individual rights

Leadership

- Government decisions should determine when to apply emergency law, with references made to the relevant principles identified in the ethics framework
- Differences in national economic contexts will affect policy implementation. European leadership is required to address differences in available resources in different countries
- Political and public health leadership is essential in determining how the ethics framework is applied in practice

Multi-stakeholder involvement

- There should be involvement of many different stakeholders including local and national agencies. Experience from national authorities is crucial, as they have faced first-hand the difficulties of dealing with emergency situations in their contexts
- Local understanding must inform decisions taken at a higher level. If a top-down approach is adopted, there must be a bottom-up feedback mechanism
- Each nation will have specific legal implications that will affect how decisions can be implemented at a local/national level

Timing and flexibility

- The ethics framework should guide decisions at the preparedness and/or planning stage, as opposed to the response stage
- A consistent approach to pandemic response should be agreed on at the preparedness stage (e.g., by creating a standard of best practices, tools, and techniques to apply) and encouraging relevant authorities to adopt and adapt
- There must be flexibility built into the framework to allow different nations to make decisions about their own circumstances and local implications

Social impacts

- Pandemics impact several other sectors such as education and employment. The ethics framework should account for the horizontal and vertical nature of emergency situations
- Social impacts should be considered, when deciding on establishing norms. Any restrictions of rights should respect boundaries and set limits concerning violations of human rights

II. Pandemic communications and information

Recommendation 2:	**Messages should be consistent, clear, and understandable; and communication should be done using culturally appropriate methods and materials tailored to be accessible to various social groups**
Recommendation 3:	**Risk communication and community engagement needs to clearly define vulnerable persons, be two-way, and engage local, regional and national partner organisations (WHO, 2020b)**
Recommendation 4:	**Coordination with policymakers, influential social media leaders, local / community leaders, women and youth groups, religious and elders' groups, local and international NGOs, health experts and practitioners, volunteers, and people with experience of pandemic diseases is key in disseminating information to all (WHO, 2020b)**
Recommendation 5:	**Misinformation should be addressed through media surveillance, feedback, emergency anthropology studies, and other social science tools (WHO, 2021c)**
Recommendation 6:	**Educate communities about the complex realities of pandemics and good pandemic management, to enhance public understanding of pandemic decisions, and to promote receptivity and compliance with messages delivered by public health authorities**

Recommendations 3 and 4 were initially proposed by the WHO in 2020, and recommendation 5 is part of the *"WHO integrated model for Emergency Risk Communication"* (WHO, 2021c). These recommendations are re-emphasised in this deliverable based on the findings from the literature review on ELSI in pandemic preparedness and response. The WHO definition of risk communication includes communication before, during and after a pandemic (WHO, 2021c). As such, Recommendation 6 emphasises the importance of enabling the general population to understand the complexities of pandemics and the basic principles that underlie the decisions made during pandemic management.

Issues relating to pandemic communication are discussed in more detail in WP5 (D5.1) of the PANDEM-2 project, where further recommendations and a common risk communication framework are being proposed. Considerations relevant to these recommendations are summarised in Box 3 below.

Box 3: Considerations for recommendations on communication and information

Resource availability

- Efforts need to be made to ensure that countries have the appropriate expertise and resources to be able to implement these recommendations
- The WHO 2018 risk communication manual is a useful tool to inform best practices in communication during emergency response

Political context

- Political regimes will greatly influence the way countries respond to emergency situations, and these regimes will determine the social, cultural, and legal frameworks that responders/managers work in

Multi-stakeholder involvement

- Public and civil society organisations (including social groups such as religious group representatives and LGBTQ+ communities) should be involved in the decision-making process

Cross-sector understanding

- There needs to be a shared understanding between technical and political stakeholders, based on trust and open discussions regarding decisions and implications.
- There should be transparency in defining reasons for decisions made

Sources of information

- The primary sources of information of various vulnerable populations need to be considered, as some information sources are more unreliable or prone to misinformation than others.

III. Legislations

Recommendation 7:	**Legal policies concerning data sharing and digital contact tracing should make provisions to address ethical and legal concepts including privacy and data protection, and outline clear steps on what to do in case of data breaches**

Considerations relevant to this recommendation are summarised in Box 4a below.

Box 4a: Considerations for recommendations on legal policies concerning data sharing and digital contract tracing

Data sharing

- A clear data sharing policy which defines a minimal structure and volume of data to be shared at EU level would be beneficial.
- Data sharing needs pre-planning in emergency situations. Policies must be put in place during pandemic preparedness planning
- Boundaries for data sharing should be set and clearly communicated across member states
- Initiatives regarding data sharing, data spaces, and data governance should tie in with data sharing policies in emergency situations

Contact tracing

- Contact tracing apps would be most useful if introduced early, accepted by the population and widely used.
- There should be sufficient legislation to support the ethical and legal compliance of contact tracing apps, and more efforts should also be made to communicate this. However, it should be noted that legal frameworks do not necessarily increase uptake, or change social/cultural issues surrounding contact tracing
- Lack of trust was a major societal barrier in the uptake of contact tracing apps. Communication is key to building trust
- People are more likely to use the apps if trusted as being helpful, rather than when imposed

Recommendation 8: **National legislations concerning emergency responses should be consistent with international health regulations, to establish appropriate response procedures**

National legal provisions should be consistent with international health regulations including EU Decision 1082/2013 on serious cross border threats to health and the WHO's IHR (2005). These provisions can be used to develop emergency response task forces and legislate public health responses such as restriction of movement and mandatory quarantine. Legislation is also required to address procedures around vaccination or testing, and regulate and set standards for the health workforce, distribution of vaccines, and medical equipment allocation. Considerations relevant to this recommendation are summarised in Box 4b below.

Box 4b: Considerations for recommendations on national and international legislations concerning emergency responses

Updates to existing regulations

- Considerations should be made as to whether there are any conflicts between national and international regulations that may affect implementation in different countries
- European standards on resource allocation and vaccine distribution would be beneficial. Steps are already being taken towards developing a common EU approach to vaccine distribution (see (European Commission, 2020b). These measures will benefit from further development
- GDPR inhibits mandating technological solutions such as contact tracing in a quick and timely manner. A framework mandating the use of contact tracing while protecting data from the users would be a powerful tool for emergency pandemic response

Healthcare worker considerations

- Legislation should account for the norms/ethics of health care frontline workers

IV. Evaluation of IT systems and tools for pandemic preparedness and response

Recommendation 9: **IT systems and tools used for pandemic preparedness and response (such as predictive modelling tools, epidemic surveillance systems and contact tracing apps) need to be constantly evaluated, updated, and re-evaluated to ensure that they are effective and meet appropriate ethical and legal standards**

The evaluation process for IT systems and tools – especially novel tools being developed for pandemic preparedness and response – should involve developers, model designers, and those concerned with

the legal and ethical issues associated with them. Considerations relevant to this recommendation are summarised in Boxes 5a and 5b below.

Box 5a: Considerations for developers and technology experts on tech evaluations

Relevance and effectiveness

- Contact tracing apps were useful, but not very effective e.g., the apps did not work in some places, or notifications were not very useful; a limited use by the population has negatively impacted on the benefit and their final outcome (contribution to limit the spread of viral transmission)
- End users would find such apps more appealing, hence use it, if they could help avoid disease, receive access to statistics and show areas of high transmission rates

Technical issues

- Technical issues with contact tracing apps were problematic
- Apps should be improved from past iterations

Modelling data

- Modelling often uses synthetic or simulated data, which mitigates ethical concerns to some extent. However, it is important that models be accurate and reflect reality

Box 5b: Considerations for policy makers on tech evaluations

- Technological developments are difficult to predict as changes happen quickly
- Creating stable and reliable digital technologies quickly in a fast-changing pandemic context is difficult and has drawbacks
- Ethical and legal experts should be involved in the development process with tech experts and representative end-users
- Legislations should be more specific on when and how to evaluate digital technologies and tools used for pandemic response (e.g., whether during or between pandemics)
- The uniqueness of each pandemic problem and specific tool/system should be considered e.g., evaluation of tools has different ('less stringent') legal implications compared to those for surveillance systems
- The availability and preparedness of experts and resources (e.g., ad-hoc locations and equipment) required to conduct evaluations when needed is a potential challenge

V. Further research

Recommendation 10	**Further research is required to inform the development and implementation of digital technologies and tools used for pandemic preparedness and response, to ensure they are compliant with relevant ethical and legal principles, and consider varying and diverse population needs**

Technology will continue to advance, and there is a need to be prepared for continuous advancements. Further research will be useful in identifying and addressing ethical, legal, and social issues associated with the development and implementation of these technologies. This should also consider varying and diverse population needs, sociocultural status, and regulatory and legal governance to promote trust building between developers, implementers, and end-users. Considerations relevant to this recommendation are summarised in Box 6 below.

Box 6: Further research should address the following issues:

- Exclusion characteristics and biased information, and their implications on health data. For example, contact tracing does not necessarily work on all devices, or for people without mobile phones
- Measures to develop and promote tools in other languages
- Practical needs of end-users from pandemic-related digital tools and technologies (e.g., what do soldiers or health professionals etc. need from these tools?)
- Strategies to promote trust-building and exchange of feedback between developers, implementers, and end users
- Diverse population needs of different social groups

5.2. Implications for PANDEM-2

The aim of the PANDEM-2 project (as described in Section 2.3) is to assist pandemic managers and relevant authorities in making rapid, evidence-based decisions in response to pandemics, and to supply them with the resources needed to communicate these decisions effectively to citizens. This will be done by implementing an IT system designed to support the needs of pandemic managers, such that they will be well positioned to respond to future pandemics. The system will include an online dashboard embedded with high-priority tools for pandemic spread prediction, visual analytics, resource management and health workforce capacity mapping. The project will also demonstrate the capture and integration of pandemic-relevant data from numerous sources, including participatory surveillance systems such as Influenzanet, and social media (e.g., Twitter and Reddit). ELSI issues and recommendations from 5.1 above which are of relevance to the PANDEM-2 project are discussed below.

1. **Ethics framework:**

Privacy and data protection were identified as some of the major ethical and legal concerns for pandemic preparedness and response. These issues are relevant to the PANDEM-2 project, as it involves the collection and processing of various types of data from different sources, including open-source, real, synthetic, abstract and research data. Examples of these include surveillance data from traditional sources (e.g., TESSY or national public health agencies) and non-traditional sources (e.g., social media); data related to system capacity and resources (e.g., weather and climate, mobility, countermeasures, and communications); and data stored in repositories (e.g., research, training material and policy data) and open access /public databases (ECDC, NCBI). The ethics requirements for PANDEM-2 are detailed in WP8 (D8.2), alongside appropriate measures taken to ensure that the project meets all relevant privacy and data protection requirements. The PANDEM-2 project also includes a Privacy Impact Assessment task that outlines privacy and data protection considerations when designing, testing, and deploying the PANDEM-2 database and tools. An ethics framework that sets out relevant ethical principles to be prioritised during pandemic preparedness planning and response (Recommendation 1) would be beneficial to PANDEM-2, as it could provide a foundation for the discourse on ethical issues to consider and inform standards for ethical practice.

2. **Data sharing legislations**

WP2 (Surveillance) of the PANDEM-2 project outlines how the database and tools will be managed. In summary, each time PANDEM-2 is installed, it will be controlled by an authorised end-user or organisation that will act as the data controller, who will also be responsible locally for defining which data and dashboards will be accessible to end-users. In so doing, the data controller takes responsibility for ensuring that private and public data will be used and accessed according to local legal and organisational regulations. The data controller will also regulate the sharing of data between organisations. This recommendation on legislations for data sharing (Recommendation 7) will guide these procedures and set boundaries, to ensure compliance with appropriate ethical and legal standards. In addition, policies defining standards for data sharing in public health emergencies including what and how much data should be made available and limits to data sharing would help reduce barriers in accessing relevant data for the development of tools such those being developed by PANDEM-2.

3. **Evaluation**

The PANDEM-2 dashboard and tools are technologies being developed for the purpose of pandemic preparedness and response. Recommendation 9 on evaluation informs the PANDEM-2 consortium of the need to evaluate and constantly update such tools and the importance of engaging ethical and legal experts in the process. Such evaluation will help reveal limitations of the tools, and lessons learned from these will be useful in subsequent pandemics. Trust building and information exchange between developers and end-users is also highlighted in this recommendation. The usability of the tools developed is a key element to consider, as end-users may be reluctant to learn about complex non-user-friendly systems especially in urgent pandemic situations where decisions need to be made quickly. These issues are being addressed through discussions with the PANDEM-2 technological team,

and a privacy impact assessment report which outlines any associated risks and their mitigation measures (WP3, Task 3.5 – privacy, social and ethical impact assessments).

4. Further research

As Recommendation 10 highlights, the PANDEM-2 project team should be aware of and prepared for continuous changes and advancements in technology. Research will be instrumental in identifying and addressing ELSI associated with the tools developed at all stages of the project. Research will also ensure that the tools developed are inclusive and consider the needs of diverse population groups. The issues of inclusivity and population needs are also being addressed through discussions with the PANDEM-2 technological team, and the privacy impact assessment report (WP3, Task 3.5 – privacy, social and ethical impact assessments).

5. Pandemic communications and information

To test the PANDEM-2 system, pandemic managers and first responders from multiple Member States will work together in EU-wise demonstrations, planning and responding to several pandemic scenarios, from Ebola to SARS/MERS CoV, to pandemic influenza, while also networking and building relationships across borders and organisations. Recommendations 2-6 on pandemic communications and information are relevant to these plans.

Table 3 below identifies ELSI associated with specific pathogens that will be involved in the demonstrations of the PANDEM-2 system (Ebola, novel influenza and SARS-like viruses). It is important for PANDEM-2 project and pandemic managers to be aware of these issues, ahead of the demonstrations and scenario planning discussions. The table also highlights where applicable, how the PANDEM-2 project will address some of the issues reported.

Table 3: ELSI associated with Ebola, novel influenza and SARS-like viruses and implications for PANDEM-2

Ethical research

- Concerns about the ethical recruitment of participants for pandemic-related research were identified during Ebola (Rid & Emanuel, 2014), novel influenza (Simpson et al., 2019) and SARS-like virus (Sharma et al., 2020; Villarosa et al., 2021) – e.g., for vaccine trials. The development of the PANDEM-2 system involves the collection and processing of various types of data including research data (e.g., surveys and interviews), which must be handled ethically.

Privacy, confidentiality and data protection

- Public concerns may arise about lack of privacy protection, data integrity and autonomy when utilising infectious disease digital surveillance systems such as the one being developed by PANDEM-2. This issue was reported during the Ebola epidemic (Desclaux et al., 2017; Zhao et al., 2021) as well as COVID-19 (Lucivero et al., 2020; Van Kolfschooten & de Ruijter, 2020).

- Health professionals may also be reluctant to disclose patient data to public health units as was the case with novel influenza and COVID-19 due to concerns about the extent to which

public health agencies are trusted to protect health information (El Emam et al., 2011; Holland et al., 2022). These issues must be prioritised during the development, implementation, and testing of the PANDEM-2 system.

Protection of the public & solidarity

- One of the most effective ways to mitigate the impacts of public health emergencies is to ensure effective country-level preparedness through the implementation of the IHR (WHO, 2021b). Under the IHR, member states are obliged to develop and maintain minimum core capacities for surveillance and response to potential public health threats; and the success of the IHR in ensuring global public health security depends on the full application, implementation, and compliance by all member states (WHO, 2021b). The PANDEM-2 system will provide a valuable resource for detecting, assessing, and responding to public health threats in EU member states.

- Jacobsen et al. (2016) identified the need to support medical and public health systems to improve local and international responses to epidemics. This support will be instrumental to the success of PANDEM-2.

- Jacobsen et al. (2016) also identified a need for expansion of predictive modelling and increased disease surveillance activities, to which the PANDEM-2 tools will provide a solution.

Vulnerable groups

- There is a need to better communicate with migrant populations by increasing the availability of information in multiple languages, including information on prevention guidelines and healthcare entitlements (Maldonado et al., 2020). With the PANDEM-2 system and tools being developed in English, consideration should be given to the needs of non-English-speaking pandemic managers and public health authorities in the EU.

5.3. Strengths and limitations

This report is based on a robust search of the literature on ELSI in pandemic preparedness and response. The project team consists of experts from diverse professional backgrounds relevant to public health emergencies (including public health research, epidemiology, psychology, and social sciences), as well as stakeholders with knowledge and expertise in pandemic preparedness and response in European contexts. There were no external stakeholders representing social groups during the ELSI workshop. However, WP5 – Pandemic Communication of the PANDEM-2 project which focuses more extensively on pandemic communication has engaged these groups in their discussions.

5.4. Conclusion

This report has reviewed the ethical, legal and social implications of pandemics and pandemic responses, and explored how these apply to the equitable distribution of resources, the prioritisation of public good vs individual rights, the sharing of data and resources across organisations and geographic boundaries and the consideration of vulnerable groups. Drawing on lessons from previous pandemics, recommendations have been made on measures that can be taken to address these ELSI risks, and to mitigate or avoid any harms to societal values and fundamental rights. The report has

also highlighted the value that the PANDEM-2 project brings in regard to pandemic preparedness in European countries and discusses issues of relevance to the PANDEM-2 consortium, to ensure that the project does not further contribute to ELSI risks.

6. Appendices

Appendix A: Questions discussed with end-users based on themes from *PANDEM D4.2*

Equitable distribution of resources

- How did your organisation/country deal with scarcity of resources? (e.g., shortage of hospital beds for non-COVID-19 patients?)
- Do you know if an ethical framework/ decision-making tool was used during the response phase to balance individual and population rights?
- Based on your experience during the COVID-19 pandemic how do feel a technology, like the PANDEM-2 dashboard, would help you better allocate scarce resources? How do you think it would help in the preparedness stage?
- Do you think an individual's gender, age, or economic status will influence how accurate a predictive modelling tool (PANDEM-2) can be in resource allocation?
- Stockpiling of resources: was this done by your region/country? Do you think it is morally acceptable to do this if other countries (not just in the EU) need these resources? Is there an opportunity to collaborate with these countries & what is the best way to do so? Something to be done in the preparedness or response stage?
- Allocation of vaccines: was the approach to vaccinate the elderly & vulnerable first accepted by society in your country/region?
- Mandatory vaccination to enter premises or attend shows/festivals – (fining or making it illegal to sit/drink indoors is removing people's autonomy to live their daily lives & not be vaccinated – is this forcing people or is it just for public health?)
- Is the vaccination of children an area of concern to your organisation/nation? Mandatory vaccination of healthcare workers – taking away their autonomy for the health of others just because of their profession? – is there a legal/ethical basis for compelling someone to disclose their vaccination status in order to abide by H&S regulations?
- Vaccination comes down to personal choice. However, if a person chooses to be vaccinated are we then impinging on their right to fair working conditions by creating a work environment whereby there is no onus on disclosing vaccinations status?
- How will PANDEM-2 dashboard & predictive modelling benefit (e.g., prevent lockdown) pandemic preparedness?

Isolation, quarantine, border control & social distancing

- Do you think isolation, quarantine or border control measures were adopted well in your country? Why or why not?
- How was traveling across borders dealt with in cases where working from home was not possible, was there any resistance to how this monitored or is it invading an individual's privacy asking them why/where they are travelling?)
- Social acceptance of the government's authority to remove an individual's right to freedom of movement: Was there any social unrest (protests) and how was this dealt with?
- When should borders open/close based on a COVID-19 outbreak and how could organisations/government better deal with this for future? Guiding documents on this? Hotel quarantine enforcement & individual responsibility (who pays?) and compliance to self-isolation for the required number of days?
- Enforcement of social distancing & mandatory mask wearing: Do either measures impact certain groups more than others (e.g., adults who are carers to their parents or individuals that are deaf are rely on lip reading)?
- Individuals not self-isolating after traveling or being a close contact because they need to work to keep a roof over their head is there information available on this: How was social welfare payments communicated to citizens based on being a close contact (e.g. food factory general operatives)?

Communication

- Has any resources or announcement been made by government or public health authorities about the access of reliable information? Is reliable information available in different formats, languages, etc.?
- Has any research or insights been found on the spread of misinformation nationally/regionally?
- What level of information was the public entitled to (e.g. specific location of outbreak)?

Surveillance

- Do you think individuals would be surprised to know that their social media posts were being used as a surveillance method of disease outbreak?
- Do you think the surveillance of social media post would be a true reflectance of what is going happening on ground or do you think it would just capture what is happening to individuals of a specific gender, sex, ethnicity, or social status?
- Surveillance of social media: Do you think the opportunities will be easy to practically implement? How would you know that information on social media was accurate or not?
- Do you think private direct messaging apps would provide any beneficial information from a surveillance point of view?
- Contact tracing apps: did they work (i.e. were they evaluated): Was there the workforce capacity & how to plan for this?
- Are there any opportunities to use this type of system in the preparedness stage? (Timing of identifying a close contact).
- Do I as a parent have the right to know if my son/daughter has been a close contact?
- Accuracy of data & reporting: Decision-making of government based on case numbers from previous day(s) & public health measures implemented as result, is this the best approach to take?
- Were there any guiding factors on when public health measures should be reduced or alleviated? What were the obstacles and what worked well?

Other

Are there any other ethical/legal issues or opportunities that were the source of discussion during the pandemic?

- Right to education or childcare? Vulnerable children left at home in potentially vulnerable situations, food poverty heightened due to no school meals, etc.
- Prioritising public health over individual health (e.g., ceasing of breast check screening or cancelling elective procedures?) – any lessons learned from this or how could the PANDEM-2 dashboard help with this?
- Did certain response measures introduced impact certain members of society more than others? How could this be mitigated in pandemic preparedness?
- Benefits/opportunities from pandemic and/or tools used? For example, working from home is now more acceptable – reduces the amount of traffic (CO_2 emissions), removes dependency to live in urban area and may allow people to move to more rural areas which increases economy in these areas.

Appendix B1: ELSI workshop agenda

Agenda item		Time
1.	Welcome & introductions	10:00 – 10:20
2.	Summary of findings on ELSI in pandemic planning & response	10:20 – 10:35
3.	Outline of group discussion process	10:35 – 10:40
4.	First round of group discussions	10:40 – 11:00
5.	Summary of feedback from each group	11:00 – 11:10
	Break	**11:10 – 11:20**
6.	Second round of group discussions	11:20 – 11:40
7.	Summary of feedback from each group	11:40 – 11:50
	Break	**11:50 – 11:55**
8.	Third round of group discussions	11:55 – 12:15
9.	Summary of feedback from each group	12:15 – 12:25
10.	General discussion	12:25 – 12:50
11.	Next steps & close	12:50 – 13:00

Appendix B2: Questions discussed at the ELSI workshop

Relevance:

- How relevant is this recommendation to your work?
- Why do you consider it relevant/irrelevant?

Content & clarity

- How does this recommendation address some of the ELSI in pandemic planning and response?
- How can the recommendation be enhanced e.g., to make it clearer/more specific/address any gaps?

Feasibility & implications

- What are the important considerations to be aware of e.g., relating to its feasibility, practical application, implementation challenges (e.g., resources required: human, financial and time), legal considerations, etc?
- Are there any groups that may be adversely affected or unduly burdened by this recommendation?

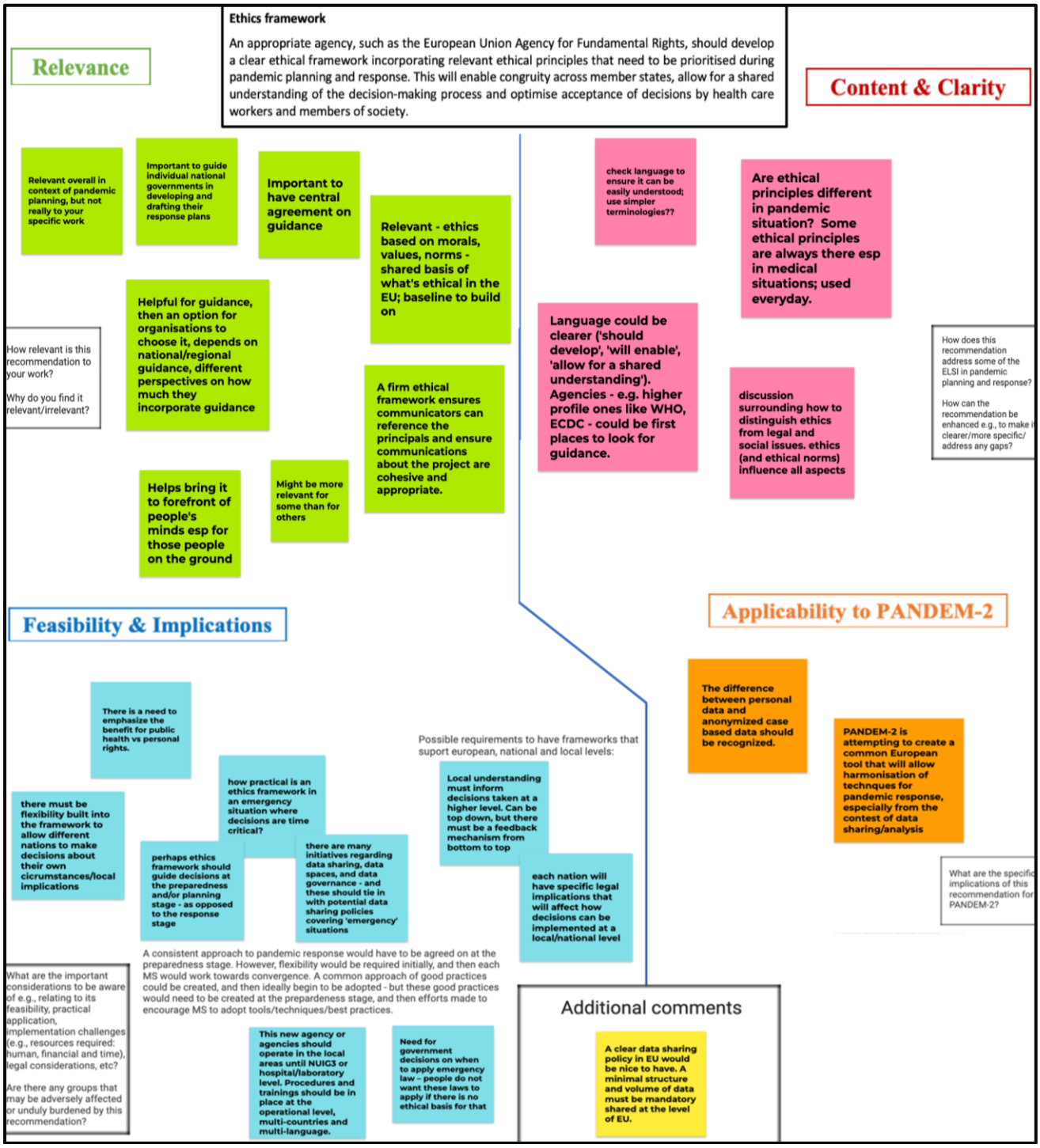
Applicability to PANDEM-2

- What are the specific implications of this recommendation for PANDEM-2?

Further suggestions

- Suggestions on any further recommendations to include in the report

Appendix B3: Sample discussions from ELSI workshop (screenshots from Jam board)



Appendix C1: National (EU) and international frameworks addressing the equitable distribution of resources in pandemic planning and response

International

- WHO International Treaty/Framework Convention for pandemic preparedness and response: https://apps.who.int/gb/COVID-19/pdf_files/2021/18_03/Item2.pdf
- WHO SAGE values framework for the allocation and prioritisation of COVID-19 vaccination: https://www.who.int/publications/i/item/who-sage-values-framework-for-the-allocation-and-prioritization-of-covid-19-vaccination
- Ethical Framework for WHO's work in the ACT-Accelerator: https://www.who.int/publications/i/item/WHO-2019-nCoV-ACT-Accelerator-Ethical_framework-2021.1
- National Academies of Sciences, Engineering, and Medicine Framework for Equitable Allocation of COVID-19 Vaccine (2020): https://www.nationalacademies.org/our-work/a-framework-for-equitable-allocation-of-vaccine-for-the-novel-coronavirus

Europe

- Joint Opinion Improving pandemic preparedness and management: https://op.europa.eu/en/publication-detail/-/publication/b6bbab7d-5a09-11eb-b59f-01aa75ed71a1/language-en/format-PDF/source-191038315
- The Lancet Regional Health Europe - Rethinking COVID-19 vaccine allocation: it is time to care about our neighbours: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8633795/

National (EU)

- **Ireland** – Ethical Framework for Decision Making in a Pandemic: https://www.gov.ie/en/publication/dbf3fb-ethical-framework-for-decision-making-in-a-pandemic/
- **Italy:** SIAARTI-SIMLA Clinical Ethics recommendations for the allocation of intensive care treatments, in exceptional, resource-limited circumstances: https://www.minervamedica.it/en/journals/minerva-anestesiologica/article.php?cod=R02Y2020N05A0469
- **Sweden** - Swedish National Council on Medical Ethics (Smer) Ethical choices in a pandemic: https://smer.se/wp-content/uploads/2020/08/smer-2020_3-english-report_webb.pdf
- **Estonia** – Ethical Framework for COVID-19 vaccination: https://rm.coe.int/ebin-vaktsineerimise-seisukohad-15-12-25333-/1680a0e999

Appendix C2: National (EU) and international frameworks addressing the prioritisation of public good vs individual rights

International

- WHO Policy Brief COVID-19 and Mandatory vaccination: Ethical considerations and caveats: https://www.who.int/publications/i/item/WHO-2019-nCoV-Policy-brief-Mandatory-vaccination-2022.1

- WHO guidelines on ethical issues in public health surveillance (2017): https://www.who.int/publications/i/item/who-guidelines-on-ethical-issues-in-public-health-surveillance

Europe

- Joint Opinion Improving pandemic preparedness and management: https://op.europa.eu/en/publication-detail/-/publication/b6bbab7d-5a09-11eb-b59f-01aa75ed71a1/language-en/format-PDF/source-191038315

National (EU)

- **Ireland –** Ethical Framework for Decision Making in a Pandemic: https://www.gov.ie/en/publication/dbf3fb-ethical-framework-for-decision-making-in-a-pandemic/

- **Sweden -** Swedish National Council on Medical Ethics (Smer) Ethical choices in a pandemic: https://smer.se/wp-content/uploads/2020/08/smer-2020_3-english-report_webb.pdf

7. References

Age UK. (2020). Age UK research lays bare the drastic impact of the pandemic on our older population's health and morale. *Age UK Media Centre [online]*, *16*.

Almeida, B., Cohen, M. A., Stone, R. I., & Weller, C. E. (2020). The demographics and economics of direct care staff highlight their vulnerabilities amidst the COVID-19 pandemic. *Journal of Aging & Social Policy*, *32*(4-5), 403-409.

Altman, B. M. (2014). Definitions, concepts, and measures of disability. *Annals of epidemiology*, *24*(1), 2-7.

Andrews, E. E., Ayers, K. B., Brown, K. S., Dunn, D. S., & Pilarski, C. R. (2021). No body is expendable: Medical rationing and disability justice during the COVID-19 pandemic. *American Psychologist*, *76*(3), 451.

Angehrn, Z., Sostar, J., Nordon, C., Turner, A., Gove, D., Karcher, H., . . . de Reydet-de Vulpillieres, F. (2020). Ethical and Social implications of using predictive modeling for Alzheimer's disease prevention: a systematic literature review. *Journal of Alzheimer's Disease*, *76*(3), 923-940.

Armitage, R., & Nellums, L. B. (2020). COVID-19 and the consequences of isolating the elderly. *The Lancet Public Health*, *5*(5), e256.

Arya, N., Redditt, V. J., Talavlikar, R., Holland, T., Brindamour, M., Wright, V., Rashid, M. (2021). Caring for refugees and newcomers in the post–COVID-19 era: Evidence review and guidance for FPs and health providers. *Canadian Family Physician*, *67*(8), 575-581.

Bailey, J., Flynn, A., & Henry, N. (2021). Pandemics and systemic discrimination: Technology-facilitated violence and abuse in an era of COVID-19 and antiracist protest. In *The Emerald international handbook of technology-facilitated violence and abuse* (pp. 787-797). Emerald Publishing Limited.

Bajos, N., Jusot, F., Pailhé, A., Spire, A., Martin, C., Meyer, L., Carrat, F. (2021). When lockdown policies amplify social inequalities in COVID-19 infections: evidence from a cross-sectional population-based survey in France. *BMC Public Health*, *21*(1), 1-10.

Baptist, A. P., Lowe, D., Sarsour, N., Jaffee, H., Eftekhari, S., Carpenter, L. M., & Bansal, P. (2020). Asthma disparities during the COVID-19 pandemic: a survey of patients and physicians. *The Journal of Allergy and Clinical Immunology: In Practice*, *8*(10), 3371-3377. e3371.

Bardosh, K., de Figueiredo, A., Gur-Arie, R., Jamrozik, E., Doidge, J., Lemmens, T., Baral, S. (2022). The unintended consequences of COVID-19 vaccine policy: why mandates, passports and restrictions may cause more harm than good. *BMJ Global Health*, *7*(5), e008684.

Bavel, J. J. V., Baicker, K., Boggio, P. S., Capraro, V., Cichocka, A., Cikara, M., Druckman, J. N. (2020). Using social and behavioural science to support COVID-19 pandemic response. *Nature human behaviour*, *4*(5), 460-471.

Bayer, R. (2007). The continuing tensions between individual rights and public health: Talking point on public health versus civil liberties. *EMBO reports*, *8*(12), 1099-1103.

Baylis, F., & Kofler, N. (2021). Vaccination certificates could entrench inequality. *Nature*, *591*(7851), 529-530.

BBC News. (2022). Covid: Austria suspends compulsory vaccination mandate. https://www.bbc.co.uk/news/world-europe-60681288

Beaney, T., Neves, A. L., Alboksmaty, A., Ashrafian, H., Flott, K., Fowler, A., Darzi, A. (2022). Trends and associated factors for Covid-19 hospitalisation and fatality risk in 2.3 million adults in England. *Nature Communications*, *13*(1), 1-10.

Beauchamp, C. (1994). Beauchamp TL, Childress JF Principles of biomedical ethics. In: Oxford.

Becker1999 (2020) An anti-lockdown protester in April 2020. https://en.wikipedia.org/wiki/Protests_against_responses_to_the_COVID-19_pandemic#/media/File:OPEN_our_OHIO_IMG_0144_(49790376873).jpg

Behaviours, I. S. P. I. G. o. (2020). Public Health Messaging for Communities from Different Cultural Backgrounds. In.

Bell, B. (2022). *Austria's Covid vaccine law comes into force amid resistance*. https://www.bbc.co.uk/news/world-europe-60155635

Benjamin, G. C., & Moulton, A. D. (2008). Public health legal preparedness: a framework for action. *The Journal of Law, Medicine & Ethics*, *36*(1_suppl), 13-17.

Bernardi, F., Cozzani, M., & Zanasi, F. (2021). Social inequality and the risk of living in a nursing home: implications for the COVID-19 pandemic. *Genus*, *77*(1), 1-16.

Bhaskaran, K., Bacon, S., Evans, S. J., Bates, C. J., Rentsch, C. T., MacKenna, B., Morton, C. E. (2021). Factors associated with deaths due to COVID-19 versus other causes: population-based cohort analysis of UK primary care data and linked national death registrations within the OpenSAFELY platform. *The Lancet Regional Health-Europe*, *6*, 100109.

Billings, J., Ching, B. C. F., Gkofa, V., Greene, T., & Bloomfield, M. (2021). Experiences of frontline healthcare workers and their views about support during COVID-19 and previous pandemics: A systematic review and qualitative meta-synthesis. *BMC health services research*, *21*(1), 1-17.

Boyd, M. (2020). RPS guidance on ethical, professional decision making in the Covid-19 Pandemic.

Brennan, C., & McConnell, D. (2020). *Covid-19: Council broke the law by using drones to monitor public movement*. https://www.irishexaminer.com/news/arid-40059233.html

Brooks, S. K., Dunn, R., Amlôt, R., Rubin, G. J., & Greenberg, N. (2017). Social and occupational factors associated with psychological wellbeing among occupational groups affected by disaster: a systematic review. *Journal of mental health*, *26*(4), 373-384.

Brown, N. J., Wilson, B., Szabadi, S., Quon, C., Ong, V., Himstead, A., Shahrestani, S. (2021). Ethical considerations and patient safety concerns for cancelling non-urgent surgeries during the COVID-19 pandemic: a review. *Patient Safety in Surgery*, *15*(1), 1-9.

Burström, B., & Tao, W. (2020). Social determinants of health and inequalities in COVID-19. In (Vol. 30, pp. 617-618): Oxford University Press.

Burton-Jeangros, C., Duvoisin, A., Lachat, S., Consoli, L., Fakhoury, J., & Jackson, Y. (2020). The impact of the Covid-19 pandemic and the lockdown on the health and living conditions of undocumented migrants and migrants undergoing legal status regularization. *Frontiers in public health*, *8*, 940.

Capron, A. M. (2007). Ethical Issues in Pandemic Planning and Response. Ethical and Legal Considerations in Mitigating Pandemic Disease: Workshop Summary [e-book edition],

Cave, S., Whittlestone, J., Nyrup, R., & Calvo, R. A. (2021). Using AI ethically to tackle covid-19. *bmj*, *372*.

Chander, R., Murugesan, M., Ritish, D., Damodharan, D., Arunachalam, V., Parthasarathy, R., Bada Math, S. (2021). Addressing the mental health concerns of migrant workers during the COVID-19 pandemic: An experiential account. In (Vol. 67, pp. 826-829): SAGE Publications Sage UK: London, England.

Chandler-Jeanville, S., Nohra, R. G., Loizeau, V., Lartigue-Malgouyres, C., Zintchem, R., Naudin, D., & Rothan-Tondeur, M. (2021). Perceptions and experiences of the COVID-19 pandemic amongst frontline nurses and their relatives in France in six paradoxes: a qualitative study. *International Journal of Environmental Research and Public Health*, *18*(13), 6977.

Cheah, C. S., Wang, C., Ren, H., Zong, X., Cho, H. S., & Xue, X. (2020). COVID-19 racism and mental health in Chinese American families. *Pediatrics*, *146*(5).

Cho, H., Ippolito, D., & Yu, Y. W. (2020). Contact tracing mobile apps for COVID-19: Privacy considerations and related trade-offs. *arXiv preprint arXiv:2003.11511*.

Cohen, J. (2020). Chinese researchers reveal draft genome of virus implicated in Wuhan pneumonia outbreak. *Science*, *11*.

Commission of European Communities. (2005). Communication from the Commission to the Council, the European parliament, the European economic and social committee and the committee of the regions. In.

Courtney, B., Hodge Jr, J. G., Toner, E. S., Roxland, B. E., Penn, M. S., Devereaux, A. V., Powell, T. (2014). Legal preparedness: care of the critically ill and injured during pandemics and disasters: CHEST consensus statement. *Chest*, *146*(4), e134S-e144S.

COVIDSurg Collaborative. (2020). Elective surgery cancellations due to the COVID-19 pandemic: global predictive modelling to inform surgical recovery plans. *Journal of British Surgery*, *107*(11), 1440-1449.

Coyer, L., Wynberg, E., Buster, M., Wijffels, C., Prins, M., Schreijer, A., Leenstra, T. (2021). Hospitalisation rates differed by city district and ethnicity during the first wave of COVID-19 in Amsterdam, the Netherlands. *BMC Public Health*, *21*(1), 1-9.

Crawshaw, A. F., Deal, A., Rustage, K., Forster, A. S., Campos-Matos, I., Vandrevala, T., Kinsman, J. (2021). What must be done to tackle vaccine hesitancy and barriers to COVID-19 vaccination in migrants? *Journal of travel medicine*, *28*(4), taab048.

Creese, J., Byrne, J.-P., Conway, E., Barrett, E., Prihodova, L., & Humphries, N. (2021). "We all really need to just take a breath": composite narratives of hospital doctors' well-being during the COVID-19 pandemic. *International journal of environmental research and public health*, *18*(4), 2051.

Czeisler, M. É., Lane, R. I., Petrosky, E., Wiley, J. F., Christensen, A., Njai, R., Barger, L. K. (2020). Mental health, substance use, and suicidal ideation during the COVID-19 pandemic—United States, June 24–30, 2020. *Morbidity and Mortality Weekly Report*, *69*(32), 1049.

Dada, S., McKay, G., Mateus, A., & Lees, S. (2019). Lessons learned from engaging communities for Ebola vaccine trials in Sierra Leone: reciprocity, relatability, relationships and respect (the four R's). *BMC public health*, *19*(1), 1-13.

Darragh, C. (2021) Anti-lockdown protest march in London, April 2021 https://en.wikipedia.org/wiki/Protests_against_responses_to_the_COVID-19_pandemic#/media/File:Anti-Lock_Down_Protest_London_(51137271728).jpg

De Boer, D. R., Hoekstra, F., Huetink, K. I., Hoekstra, T., Krops, L. A., & Hettinga, F. J. (2021). Physical activity, sedentary behavior and well-being of adults with physical disabilities and/or chronic diseases during the first wave of the COVID-19 pandemic: A rapid review. *International journal of environmental research and public health*, *18*(12), 6342.

Department of Health & Social Care. (2021). The Health and Social Care Act 2008 (Regulated Activities) (Amendment) (Coronavirus) (No. 2) Regulations 2021. In.

Desclaux, A., Badji, D., Ndione, A. G., & Sow, K. (2017). Accepted monitoring or endured quarantine? Ebola contacts' perceptions in Senegal. *Social science & medicine*, *178*, 38-45.

Desroches, M. L., Fisher, K., Ailey, S., Stych, J., McMillan, S., Horan, P., Wilson, N. (2022). Supporting the needs of people with intellectual and developmental disabilities 1 year into the COVID-19 pandemic: An international, mixed methods study of nurses' perspectives. *Journal of Policy and Practice in intellectual disabilities*, *19*(1), 48-63.

Dessie, Z. G., & Zewotir, T. (2021). Mortality-related risk factors of COVID-19: a systematic review and meta-analysis of 42 studies and 423,117 patients. *BMC infectious diseases*, *21*(1), 1-28.

Di Mattei, V. E., Perego, G., Milano, F., Mazzetti, M., Taranto, P., Di Pierro, R., Preti, E. (2021). The "healthcare workers' wellbeing (Benessere operatori)" project: A picture of the mental health conditions of italian healthcare workers during the first wave of the covid-19 pandemic. *International journal of environmental research and public health*, *18*(10), 5267.

Drefahl, S., Wallace, M., Mussino, E., Aradhya, S., Kolk, M., Brandén, M., Andersson, G. (2020). A population-based cohort study of socio-demographic risk factors for COVID-19 deaths in Sweden. *Nature communications*, *11*(1), 1-7.

Dwyer, J., & Tsai, D. F. (2008). Developing the duty to treat: HIV, SARS, and the next epidemic. *Journal of Medical Ethics*, *34*(1), 7-10.

Dyer, O. (2022). Covid-19: Ottawa declares emergency as truckers' protest continues. In: British Medical Journal Publishing Group.

ECDC. (2022). Guidance on the provision of support for medically and socially vulnerable populations in EU/EEA countries and the United Kingdom during the COVID-19 pandemic. In.

Eichelberger, L. (2007). SARS and New York's Chinatown: the politics of risk and blame during an epidemic of fear. *Social Science & Medicine*, *65*(6), 1284-1295.

El Emam, K., Mercer, J., Moreau, K., Grava-Gubins, I., Buckeridge, D., & Jonker, E. (2011). Physician privacy concerns when disclosing patient data for public health purposes during a pandemic influenza outbreak. *BMC Public Health*, *11*(1), 1-16.

Elisabeth, M., Maneesh, P.-S., & Michael, S. (2020). Refugees in Sweden during the Covid-19 pandemic—the need for a new perspective on health and integration. *Frontiers in Public Health*, 605.

Elves, C. B., & Herring, J. (2020). Ethical framework for adult social care in COVID-19. *Journal of Medical Ethics*, *46*(10), 662-667.

Emanuel, E. J. (2003). The lessons of SARS. In (Vol. 139, pp. 589-591): American College of Physicians.

Emanuel, E. J., Persad, G., Upshur, R., Thome, B., Parker, M., Glickman, A., . . . Phillips, J. P. (2020). Fair allocation of scarce medical resources in the time of Covid-19. In (Vol. 382, pp. 2049-2055): Mass Medical Soc.

Equality & Human Rights Commission. (2019). Principles for the lawful use of physical, chemical, mechanical and coercive restrictive interventions. In.

EU-FRA. (2020). Coronavirus COVID-19 Outbreak in the EU Fundamental Rights Implications. *Croatia. Centre for Peace Studies*.

European Commission. (2020a). Coronavirus accelerates drive to share health data across borders. In.

European Commission. (2020b). EU Vaccine Strategy.

European Commission. (2021). Vulnerable person.

European Data Protection Board. (2021). *EDPB Documenton response to the request from the European Commission for clarifications on the consistent application of the GDPR, focusing on health research*. https://edpb.europa.eu/sites/default/files/files/file1/edpb_replyec_questionnaireresearch_final.pdf

European Parliament. (2002). Directive 2002/58/EC of the European Parliament and of the Council of 12 July 2002 concerning the processing of personal data and the protection of privacy in the electronic communications sector, Off. *JL 201, 31.7. 2002, at 37.(Directive on Privacy and Electronic Communications)*.

Fairchild, A. L., Haghdoost, A. A., Bayer, R., Selgelid, M. J., Dawson, A., Saxena, A., & Reis, A. (2017). Ethics of public health surveillance: new guidelines. *The lancet public health*, *2*(8), e348-e349.

Fang, X., Li, S., Yu, H., Wang, P., Zhang, Y., Chen, Z., Jia, H. (2020). Epidemiological, comorbidity factors with severity and prognosis of COVID-19: a systematic review and meta-analysis. *Aging (albany NY)*, *12*(13), 12493.

Federal Ministry of Health. (2022). Current information for travelers: The Ordinance on Coronavirus Entry Regulations (Coronavirus-Einreiseverordnung – CoronaEinreiseV). In.

Fielding, J., Sullivan, S., Beard, F., Macartney, K., Williams, J., Dawson, A., Moss, R. (2021). Constructing an ethical framework for priority allocation of pandemic vaccines. *Vaccine*, *39*(5), 797-804.

Fins, J. J., & Miller, F. G. (2020). Proportionality, pandemics, and medical ethics. *The American Journal of Medicine*, *133*(11), 1243-1244.

Fisher, O. M., Brown, K. G., Coker, D. J., McBride, K. E., Steffens, D., Koh, C. E., & Sandroussi, C. (2020). Distributive justice during the coronavirus disease 2019 pandemic in Australia. *ANZ journal of surgery*.

Friedman, C. (2021). Food insecurity of people with disabilities who were Medicare beneficiaries during the COVID-19 pandemic. *Disability and Health Journal*, *14*(4), 101166.

Friedman, C. (2022). Financial hardship experienced by people with disabilities during the COVID-19 pandemic. *Disability and Health Journal*, 101359.

Gabarron, E., Oyeyemi, S. O., & Wynn, R. (2021). COVID-19-related misinformation on social media: a systematic review. *Bulletin of the World Health Organization*, *99*(6), 455.

Giusino, D., De Angelis, M., Mazzetti, G., Christensen, M., Innstrand, S. T., Faiulo, I. R., & Chiesa, R. (2022). "We All Held Our Own": Job Demands and Resources at Individual, Leader, Group, and Organizational Levels During COVID-19 Outbreak in Health Care. A Multi-Source Qualitative Study. *Workplace health & safety*, *70*(1), 6-16.

Glasper, A. (2021). Do not attempt resuscitation decisions during the COVID-19 pandemic. *British Journal of Nursing*, *30*(9), 562-563.

Goggin, G., & Ellis, K. (2020). Disability, communication, and life itself in the COVID-19 pandemic. *Health sociology review*, *29*(2), 168-176.

Goldsmith, L. P., Rowland-Pomp, M., Hanson, K., Deal, A., Crawshaw, A. F., Hayward, S. E., Razai, M. (2022). The use of social media platforms by migrant and ethnic minority populations during the COVID-19 pandemic: a systematic review. *medRxiv*.

Gorenko, J. A., Moran, C., Flynn, M., Dobson, K., & Konnert, C. (2021). Social isolation and psychological distress among older adults related to COVID-19: a narrative review of remotely-delivered interventions and recommendations. *Journal of Applied Gerontology*, *40*(1), 3-13.

GoToVan (2020) Anti-lockdown protest in Vancouver, British Columbia, on 26 April 2020 https://en.wikipedia.org/wiki/Protests_against_responses_to_the_COVID-19_pandemic#/media/File:COVID-19_Vancouver's_largest_protest,_April_26th_2020_(49823981297).jpg

Guglielmetti, P. (2016). Decision No 1082/2013/EU of the European Parliament and of the Council of 22 October 2013 on serious cross-border threats to health.

Gur-Arie, R., Jamrozik, E., & Kingori, P. (2021). No jab, no job? Ethical issues in mandatory COVID-19 vaccination of healthcare personnel. *BMJ global health*, *6*(2), e004877.

Hado, E., & Friss Feinberg, L. (2020). Amid the COVID-19 pandemic, meaningful communication between family caregivers and residents of long-term care facilities is imperative. *Journal of Aging & Social Policy*, *32*(4-5), 410-415.

Hajek, A., & König, H. H. (2022). Frequency of contact with friends and relatives via internet and psychosocial factors in middle-aged and older adults during the COVID-19 pandemic. Findings from the German Ageing Survey. *International Journal of Geriatric Psychiatry*, *37*(1).

Hargreaves, S., Zenner, D., Wickramage, K., Deal, A., & Hayward, S. E. (2020). Targeting COVID-19 interventions towards migrants in humanitarian settings. *The Lancet Infectious Diseases*, *20*(6), 645-646.

Harrison, P. W., Lopez, R., Rahman, N., Allen, S. G., Aslam, R., Buso, N., Glont, M. (2021). The COVID-19 Data Portal: accelerating SARS-CoV-2 and COVID-19 research through rapid open access data sharing. *Nucleic Acids Research*, *49*(W1), W619-W623.

Hayward, S. E., Deal, A., Cheng, C., Crawshaw, A., Orcutt, M., Vandrevala, T. F., Requena-Méndez, A. (2021). Clinical outcomes and risk factors for COVID-19 among migrant populations in high-income countries: a systematic review. *Journal of migration and health*, *3*, 100041.

Hedley, D., Hayward, S. M., Denney, K., Uljarević, M., Bury, S., Sahin, E., Robinson, J. (2021). The association between COVID-19, personal wellbeing, depression, and suicide risk factors in Australian autistic adults. *Autism Research*, *14*(12), 2663-2676.

Hendriks, A. (2007). UN Convention on the Rights of Persons with Disabilities. *European Journal of Health Law*, *14*(3), 273-298.

Hermann, T. (2020) Protester with a "Free The Bee" placard during the COVID-19 protests in Berlin on 29 August 2020, near the Brandenburg Gate. https://en.wikipedia.org/wiki/Protests_against_responses_to_the_COVID-19_pandemic#/media/File:Vicent-van-Volkmer-Bienen-Aktivist-Demo-29.08.2020_Berlin_Covid-19_Pandemie.jpg

Hill, J. (2022). *German Covid protests turn nasty in row over rules and vaccinations*. https://www.bbc.co.uk/news/world-europe-60059543

Holland, S., Cawthra, J., Schloemer, T., & Schröder-Bäck, P. (2022). Trust and The Acquisition and Use of Public Health Information. *Health Care Analysis*, *30*(1), 1-17.

House of Lords. Secondary Legislation Scrutiny Committee. 21st Report of Session 2021–22.

Houses of the Oireachtas. (2021). Health (Amendment) Act 2021.

Hoven, H., Dragano, N., Angerer, P., Apfelbacher, C., Backhaus, I., Hoffmann, B., Söhner, F. (2022). Striving for Health Equity: The Importance of Social Determinants of Health and Ethical Considerations in Pandemic Preparedness Planning. *International Journal of Public Health*, 43.

Hwang, J., Toma, C. L., Chen, J., Shah, D. V., Gustafson, D., & Mares, M.-L. (2021). Effects of web-based social connectedness on older adults' depressive symptoms: A two-wave cross-lagged panel study. *Journal of medical Internet research*, *23*(1), e21275.

Hyland-Wood, B., Gardner, J., Leask, J., & Ecker, U. K. (2021). Toward effective government communication strategies in the era of COVID-19. *Humanities and Social Sciences Communications*, *8*(1), 1-11.

Iacobucci, G. (2020). Covid-19: Doctors warn of humanitarian catastrophe at Europe's largest refugee camp. In: British Medical Journal Publishing Group.

Iacoella, F., Justino, P., & Martorano, B. (2021). *Do pandemics lead to rebellion? Policy responses to COVID-19, inequality, and protests in the USA*. WIDER Working Paper.

Indseth, T., Grøsland, M., Arnesen, T., Skyrud, K., Kløvstad, H., Lamprini, V., Kjøllesdal, M. (2021). COVID-19 among immigrants in Norway, notified infections, related hospitalizations and associated mortality: a register-based study. *Scandinavian journal of public health*, *49*(1), 48-56.

Iob, E., Steptoe, A., & Fancourt, D. (2020). Abuse, self-harm and suicidal ideation in the UK during the COVID-19 pandemic. *The British Journal of Psychiatry*, *217*(4), 543-546.

Isaacs, D., Britton, P. N., & Preisz, A. (2020). Ethical reflections on the COVID-19 pandemic: The epidemiology of panic. *Journal of Paediatrics and Child Health*, *56*(5), 690.

Jacobsen, K. H., Aguirre, A. A., Bailey, C. L., Baranova, A. V., Crooks, A. T., Croitoru, A., Narayanan, A. (2016). Lessons from the Ebola outbreak: action items for emerging infectious disease preparedness and response. *Ecohealth*, *13*(1), 200-212.

Jesus, T. S., Bhattacharjya, S., Papadimitriou, C., Bogdanova, Y., Bentley, J., Arango-Lasprilla, J. C., & Kamalakannan, S. (2021). Lockdown-related disparities experienced by people with disabilities during the first wave of the COVID-19 pandemic: Scoping review with thematic analysis. *International journal of environmental research and public health*, *18*(12), 6178.

Jetten, J., Wang, Z., Steffens, N. K., Mols, F., Peters, K., & Verkuyten, M. (2017). A social identity analysis of responses to economic inequality. *Current Opinion in Psychology*, *18*, 1-5.

Kaelen, S., van den Boogaard, W., Pellecchia, U., Spiers, S., De Cramer, C., Demaegd, G., Decroo, T. (2021). How to bring residents' psychosocial well-being to the heart of the fight against Covid-19 in Belgian nursing homes—A qualitative study. *PloS one*, *16*(3), e0249098.

Kamradt-Scott, A. (2012). Evidence-based medicine and the governance of pandemic influenza. *Global public health*, *7*(sup2), S111-S126.

Karpur, A., Vasudevan, V., Lello, A., Frazier, T. W., & Shih, A. (2021). Food insecurity in the households of children with autism spectrum disorders and intellectual disabilities in the United States: Analysis of the National Survey of Children's Health Data 2016–2018. *Autism*, *25*(8), 2400-2411.

Kass, N. E. (2005). An ethics framework for public health and avian influenza pandemic preparedness. *The Yale journal of biology and medicine*, *78*(5), 239.

Kinsman, J., de Bruijne, K., Jalloh, A. M., Harris, M., Abdullah, H., Boye-Thompson, T., Jalloh-Vos, H. (2017). Development of a set of community-informed Ebola messages for Sierra Leone. *PLoS neglected tropical diseases*, *11*(8), e0005742.

Knights, F., Carter, J., Deal, A., Crawshaw, A. F., Hayward, S. E., Jones, L., & Hargreaves, S. (2021). Impact of COVID-19 on migrants' access to primary care and implications for vaccine roll-out: a national qualitative study. *British Journal of General Practice*, *71*(709), e583-e595.

Koval, O., Engen, O. A., Kringen, J., & Wiig, S. (2021). Strategies of communicating health-related risks to vulnerable groups of immigrants during a pandemic: a scoping review of qualitative and quantitative evidence. *International Journal of Health Governance*.

Kowalewski, M. (2021). Street protests in times of COVID-19: adjusting tactics and marching 'as usual'. *Social Movement Studies*, *20*(6), 758-765.

Krieger, N. (2020). ENOUGH: COVID-19, structural racism, police brutality, plutocracy, climate change—and time for health justice, democratic governance, and an equitable, sustainable future. In (Vol. 110, pp. 1620-1623): American Public Health Association.

Kroll, J. A. (2018). Data science data governance [AI ethics]. *IEEE Security & Privacy*, *16*(6), 61-70.

Kuper, H., Banks, L. M., Bright, T., Davey, C., & Shakespeare, T. (2020). Disability-inclusive COVID-19 response: What it is, why it is important and what we can learn from the United Kingdom's response. *Wellcome open research*, *5*.

Kupferschmidt, K. (2014). Estimating the Ebola epidemic. In: American Association for the Advancement of Science.

Kuran, C. H. A., Morsut, C., Kruke, B. I., Krüger, M., Segnestam, L., Orru, K., Gabel, F. (2020). Vulnerability and vulnerable groups from an intersectionality perspective. *International Journal of Disaster Risk Reduction*, *50*, 101826.

Lanzing, M. (2021). Contact tracing apps: an ethical roadmap. *Ethics and information technology*, *23*(1), 87-90.

Larson, H. J. (2018). The biggest pandemic risk? Viral misinformation. *Nature*, *562*(7726), 309-310.

Lee, T.-L. (2020). Legal preparedness as part of COVID-19 response: the first 100 days in Taiwan. *BMJ Global Health*, *5*(5), e002608.

Leo, C. G., Sabina, S., Tumolo, M. R., Bodini, A., Ponzini, G., Sabato, E., & Mincarone, P. (2021). Burnout among healthcare workers in the COVID 19 era: a review of the existing literature. *Frontiers in public health*, *9*.

Litz, B. T., Stein, N., Delaney, E., Lebowitz, L., Nash, W. P., Silva, C., & Maguen, S. (2009). Moral injury and moral repair in war veterans: A preliminary model and intervention strategy. *Clinical psychology review*, *29*(8), 695-706.

Lowcock, E. C., Rosella, L. C., Foisy, J., McGeer, A., & Crowcroft, N. (2012). The social determinants of health and pandemic H1N1 2009 influenza severity. *American journal of public health*, *102*(8), e51-e58.

Luceño-Moreno, L., Talavera-Velasco, B., García-Albuerne, Y., & Martín-García, J. (2020). Symptoms of posttraumatic stress, anxiety, depression, levels of resilience and burnout in Spanish health personnel during the COVID-19 pandemic. *International journal of environmental research and public health*, *17*(15), 5514.

Lucivero, F., Hallowell, N., Johnson, S., Prainsack, B., Samuel, G., & Sharon, T. (2020). COVID-19 and contact tracing apps: ethical challenges for a social experiment on a global scale. *Journal of bioethical inquiry*, *17*(4), 835-839.

Lugo-Marín, J., Gisbert-Gustemps, L., Setien-Ramos, I., Español-Martín, G., Ibañez-Jimenez, P., Forner-Puntonet, M., . . . Ramos-Quiroga, J. A. (2021). COVID-19 pandemic effects in people with Autism Spectrum Disorder and their caregivers: Evaluation of social distancing and lockdown impact on mental health and general status. *Research in autism spectrum disorders*, *83*, 101757.

Maldonado, B. M. N., Collins, J., Blundell, H. J., & Singh, L. (2020). Engaging the vulnerable: a rapid review of public health communication aimed at migrants during the COVID-19 pandemic in Europe. *Journal of migration and health*, *1*, 100004.

Marseille, E., & Kahn, J. G. (2019). Utilitarianism and the ethical foundations of cost-effectiveness analysis in resource allocation for global health. *Philosophy, Ethics, and Humanities in Medicine*, *14*(1), 1-7.

Martin, R. (2008). Law, and Public Health Policy. *International Encyclopedia of Public Health*, 30.

Maurer, L. R., Perez, N. P., Witt, E. E., & Ortega, G. (2020). Protecting our own: equity for employees as hospitals battle COVID-19. *Health Equity*, *4*(1), 394-396.

May, T., Aughterson, H., Fancourt, D., & Burton, A. (2021). 'Stressed, uncomfortable, vulnerable, neglected': a qualitative study of the psychological and social impact of the COVID-19 pandemic on UK frontline keyworkers. *BMJ open*, *11*(11), e050945.

McCauley, M., Minsky, S., & Viswanath, K. (2013). The H1N1 pandemic: media frames, stigmatization and coping. *BMC Public Health*, *13*(1), 1-16.

McConnell, D. (2020). Balancing the duty to treat with the duty to family in the context of the COVID-19 pandemic. *Journal of medical ethics*, *46*(6), 360-363.

McDougall, R. J., Gillam, L., Ko, D., Holmes, I., & Delany, C. (2021). Balancing health worker well-being and duty to care: an ethical approach to staff safety in COVID-19 and beyond. *Journal of Medical Ethics*, *47*(5), 318-323.

Molloy, A. (2021). 'I am so broken' – woman whose father died on day she entered hotel quarantine refused permission to travel home to Argentina. In.

Monteiro, J. F. (2020). Distributive Justice: Lessons of a Pandemic. In. Archives of Pulmonology and Respiratory Care.

Moore, R. C., & Hancock, J. T. (2020). Older adults, social technologies, and the coronavirus pandemic: Challenges, strengths, and strategies for support. *Social media+ society*, *6*(3), 2056305120948162.

Mueller, A. L., McNamara, M. S., & Sinclair, D. A. (2020). Why does COVID-19 disproportionately affect older people? *Aging (albany NY)*, *12*(10), 9959.

Mukherjee, D., Tarsney, P. S., & Kirschner, K. L. (2022). If Not Now, Then When? Taking Disability Seriously in Bioethics. *Hastings Center Report*, *52*(3), 37-48.

Nelson, K. E., Hanson, G. C., Boyce, D., Ley, C. D., Swavely, D., Reina, M., & Rushton, C. H. (2022). Organizational impact on healthcare workers' moral injury during COVID-19: a mixed-methods analysis. *JONA: The Journal of Nursing Administration*, *52*(1), 57-66.

Nguyen, L. H., Drew, D. A., Graham, M. S., Joshi, A. D., Guo, C.-G., Ma, W., Lo, C.-H. (2020). Risk of COVID-19 among front-line health-care workers and the general community: a prospective cohort study. *The Lancet Public Health*, *5*(9), e475-e483.

Nsubuga, P., White, M. E., Thacker, S. B., Anderson, M. A., Blount, S. B., Broome, C. V., Sosin, D. (2006). Public health surveillance: a tool for targeting and monitoring interventions. *Disease Control Priorities in Developing Countries. 2nd edition*.

OECD. (2020). What is the impact of the COVID-19 pandemic on immigrants and their children? In.

OECD. (2021). *Enhancing public trust in COVID-19 vaccination: The role of governments*. OECD Publishing.

Ofsted. (2021). SEND: old issues, new issues, next steps.

Olick, R. S., Shaw, J., & Yang, Y. T. (2021). Ethical issues in mandating COVID-19 vaccination for health care personnel. Mayo Clinic Proceedings,

ONS. (2022). Updated estimates of coronavirus (COVID-19) related deaths by disability status, England: 24 January 2020 to 9 March 2022. In.

Oomen, D., Nijhof, A. D., & Wiersema, J. R. (2021). The psychological impact of the COVID-19 pandemic on adults with autism: a survey study across three countries. *Molecular Autism*, *12*(1), 1-21.

O'Sullivan, L., Aldasoro, E., O'Brien, Á., Nolan, M., McGovern, C., & Carroll, Á. (2022). Ethical values and principles to guide the fair allocation of resources in response to a pandemic: a rapid systematic review. *BMC medical ethics*, *23*(1), 1-11.

Palazzani, L. (2020). The pandemic and the ethical dilemma of limited resources: Who to treat? *Bioethics Update*, *6*(2), 67-79.

Palmer, K., Monaco, A., Kivipelto, M., Onder, G., Maggi, S., Michel, J.-P., Donde, S. (2020). The potential long-term impact of the COVID-19 outbreak on patients with non-communicable diseases in Europe: consequences for healthy ageing. *Aging clinical and experimental research*, *32*(7), 1189-1194.

Pang, B. (2021). Beyond hypervisibility and fear: British Chinese Communities' leisure and health-related experiences in the time of coronavirus. *Leisure Sciences*, *43*(1-2), 111-117.

Pannett, R. (2022). German police used a tracing app to scout crime witnesses. Some fear that's fuel for covid conspiracists. In.

Panocchia, N., D'ambrosio, V., Corti, S., Presti, E. L., Bertelli, M., Scattoni, M. L., & Ghelma, F. (2021). COVID-19 pandemic, the scarcity of medical resources, community-centred medicine and discrimination against persons with disabilities. *Journal of Medical Ethics*, *47*(6), 362-366.

Parker, M., Bedford, H., Ussher, M., & Stead, M. (2021). Should covid vaccination be mandatory for health and care staff? *bmj*, *374*.

Parker, M. J., Fraser, C., Abeler-Dörner, L., & Bonsall, D. (2020). Ethics of instantaneous contact tracing using mobile phone apps in the control of the COVID-19 pandemic. *Journal of Medical Ethics*, *46*(7), 427-431.

Paterlini, M. (2021). Covid-19: Italy sees protests against mandatory health passports for workplaces. In: British Medical Journal Publishing Group.

Paulik, L. B., Keenan, R. E., & Durda, J. L. (2020). The case for effective risk communication: Lessons from a global pandemic. *Integrated Environmental Assessment and Management*, *16*(5), 552.

Persad, G., Wertheimer, A., & Emanuel, E. J. (2009). Principles for allocation of scarce medical interventions. *The Lancet*, *373*(9661), 423-431.

Peters, D., Vold, K., Robinson, D., & Calvo, R. A. (2020). Responsible AI—two frameworks for ethical design practice. *IEEE Transactions on Technology and Society*, *1*(1), 34-47.

PGMBM. (2021). Written evidence s submitted by PGMBM (AAS0006). In.

Plagg, B., Engl, A., Piccoliori, G., & Eisendle, K. (2020). Prolonged social isolation of the elderly during COVID-19: Between benefit and damage. *Archives of gerontology and geriatrics*, *89*, 104086.

Putz, C., & Ainslie, D. (2020). Coronavirus (COVID-19) related deaths by disability status, England and Wales-Office for National Statistics. In.

Pécout, C., Pain, E., Chekroun, M., Champeix, C., Kulak, C., Prieto, R., Lainé-Pellet, A.-F. (2021). Impact of the COVID-19 Pandemic on Patients Affected by Non-Communicable Diseases in Europe and in the USA. *International Journal of Environmental Research and Public Health*, *18*(13), 6697.

Ranisch, R., Nijsingh, N., Ballantyne, A., van Bergen, A., Buyx, A., Friedrich, O., Wild, V. (2021). Digital contact tracing and exposure notification: ethical guidance for trustworthy pandemic management. *Ethics and Information Technology*, *23*(3), 285-294.

Rid, A., & Emanuel, E. J. (2014). Ethical considerations of experimental interventions in the Ebola outbreak. *The Lancet*, *384*(9957), 1896-1899.

Robert, R., Kentish-Barnes, N., Boyer, A., Laurent, A., Azoulay, E., & Reignier, J. (2020). Ethical dilemmas due to the Covid-19 pandemic. *Annals of intensive care*, *10*(1), 1-9.

Rocha, Y. M., de Moura, G. A., Desidério, G. A., de Oliveira, C. H., Lourenço, F. D., & de Figueiredo Nicolete, L. D. (2021). The impact of fake news on social media and its influence on health during the COVID-19 pandemic: A systematic review. *Journal of Public Health*, 1-10.

Rockwood, K., & Theou, O. (2020). Using the clinical frailty scale in allocating scarce health care resources. *Canadian Geriatrics Journal*, *23*(3), 210.

Rodger, D., & Blackshaw, B. P. (2022). COVID-19 vaccination should not be mandatory for health and social care workers. *The New Bioethics*, *28*(1), 27-39.

Rodrigues, N. G., Han, C. Q. Y., Su, Y., Klainin-Yobas, P., & Wu, X. V. (2022). Psychological impacts and online interventions of social isolation amongst older adults during COVID-19 pandemic: a scoping review. *Journal of Advanced Nursing*, *78*(3), 609-644.

Rodriguez, A., Tuck, C., Dozier, M. F., Lewis, S. C., Eldridge, S., Jackson, T., Weir, C. J. (2022). Current recommendations/practices for anonymising data from clinical trials in order to make it available for sharing: A scoping review. *Clinical Trials*, 17407745221087469.

Rodríguez de Limia Ramírez, K., Ruiz-Robledillo, N., Duro-Torrijos, J. L., García-Román, V., Albaladejo-Blázquez, N., & Ferrer-Cascales, R. (2021). Prevalence of SARS-CoV-2 Infection in a Sample of Health Workers in Two Health Departments of the Valencian Community in Spain. *International Journal of Environmental Research and Public Health*, *19*(1), 66.

Rogers, N. T., Waterlow, N. R., Brindle, H., Enria, L., Eggo, R. M., Lees, S., & Roberts, C. H. (2020). Behavioral change towards reduced intensity physical activity is disproportionately prevalent among adults with serious health issues or Self-Perception of high risk during the UK COVID-19 Lockdown. *Frontiers in public health*, *8*, 575091.

Rosenbaum, S. J. (2011). Ethical considerations for decision making regarding allocation of mechanical ventilators during a severe influenza pandemic or other public health emergency.

Rotarou, E. S., Sakellariou, D., Kakoullis, E. J., & Warren, N. (2021). Disabled people in the time of COVID-19: identifying needs, promoting inclusivity. *Journal of global health*, *11*.

Rubio, O., Estella, A., Cabre, L., Saralegui-Reta, I., Martin, M., Zapata, L., Trenado, J. (2020). Ethical recommendations for a difficult decision-making in intensive care units due to the exceptional situation of crisis by the COVID-19 pandemic: A rapid review & consensus of experts. *Medicina Intensiva (English Edition)*, *44*(7), 439-445.

Ryoo, N., Pyun, J.-M., Baek, M. J., Suh, J., Kang, M. J., Wang, M. J., Park, Y. H. (2020). Coping with Dementia in the Middle of the COVID-19 Pandemic. *Journal of Korean Medical Science*, *35*(42).

Röthke, N., Wollschläger, D., Kunzler, A. M., Rohde, A., Molter, S., Bodenstein, M., Tüscher, O. (2021). Mental burden, resilience and tendency towards absenteeism among healthcare personnel in Germany during the first wave of the COVID-19 pandemic in spring 2020: An ad hoc survey. *Der Nervenarzt*, 1.

Salajan, A., Tsolova, S., Ciotti, M., & Suk, J. E. (2020). To what extent does evidence support decision making during infectious disease outbreaks? A scoping literature review. *Evidence & Policy*, *16*(3), 453-475.

Salmon, D., Opel, D. J., Dudley, M. Z., Brewer, J., & Breiman, R. (2021). Reflections On Governance, Communication, And Equity: Challenges And Opportunities In COVID-19 Vaccination: Article examines the engagement and communication steps necessary to strengthen the COVID-19 vaccine roll out by federal, state, and local governments. *Health Affairs*, *40*(3), 419-425.

Salyers, M. P., Bonfils, K. A., Luther, L., Firmin, R. L., White, D. A., Adams, E. L., & Rollins, A. L. (2017). The relationship between professional burnout and quality and safety in healthcare: a meta-analysis. *Journal of general internal medicine*, *32*(4), 475-482.

Santibañez, S., Siegel, V., O'Sullivan, M., Lacson, R., & Jorstad, C. (2015). Health communications and community mobilization during an Ebola response: partnerships with community and faith-based organizations. *Public Health Reports*, *130*(2), 128-133.

Savulescu, J. (2021). Good reasons to vaccinate: mandatory or payment for risk? *Journal of medical ethics*, *47*(2), 78-85.

Savulescu, J., Vergano, M., Craxì, L., & Wilkinson, D. (2020). An ethical algorithm for rationing life-sustaining treatment during the COVID-19 pandemic. *British Journal of Anaesthesia*, *125*(3), 253-258.

Schoch-Spana, M., Bouri, N., Rambhia, K. J., & Norwood, A. (2010). Stigma, health disparities, and the 2009 H1N1 influenza pandemic: how to protect Latino farmworkers in future health emergencies. *Biosecurity and bioterrorism: biodefense strategy, practice, and science*, *8*(3), 243-254.

Scully, J. L. (2020). Disability, disablism, and COVID-19 pandemic triage. *Journal of bioethical inquiry*, *17*(4), 601-605.

Sell, T. K., Boddie, C., McGinty, E. E., Pollack, K., Smith, K. C., Burke, T. A., & Rutkow, L. (2017). Media messages and perception of risk for Ebola virus infection, United States. *Emerging infectious diseases*, *23*(1), 108.

Shakespeare, T., Ndagire, F., & Seketi, Q. E. (2021). Triple jeopardy: disabled people and the COVID-19 pandemic. *The Lancet*, *397*(10282), 1331-1333.

Shanafelt, T., Ripp, J., & Trockel, M. (2020). Understanding and addressing sources of anxiety among health care professionals during the COVID-19 pandemic. *Jama*, *323*(21), 2133-2134.

Sharma, O., Sultan, A. A., Ding, H., & Triggle, C. R. (2020). A Review of the Progress and Challenges of Developing a Vaccine for COVID-19. *Frontiers in immunology*, *11*, 585354.

Shetty, P. (2010). Experts concerned about vaccination backlash. *The Lancet*, *375*(9719), 970-971.

Simpson, C. R., Beever, D., Challen, K., De Angelis, D., Fragaszy, E., Goodacre, S., Semple, M. G. (2019). The UK's pandemic influenza research portfolio: a model for future research on emerging infections. *The Lancet Infectious Diseases*, *19*(8), e295-e300.

Skarpa, P. E., & Garoufallou, E. (2021). Information seeking behavior and COVID-19 pandemic: A snapshot of young, middle aged and senior individuals in Greece. *International journal of medical informatics*, *150*, 104465.

Smith, C. (2020). The structural vulnerability of healthcare workers during COVID-19: Observations on the social context of risk and the equitable distribution of resources. *Social Science & Medicine*, *258*, 113119.

Smith, H., Coulson-Smith, P., Kennedy, M.-R., Birchley, G., Ives, J., & Huxtable, R. (2021). Principles for pandemics: COVID-19 and professional ethical guidance in England and Wales. *BMC Medical Ethics*, *22*(1), 1-15.

Smith, M., & Upshur, R. (2019). Pandemic disease, public health, and ethics. *The Oxford handbook of public health ethics*, 797-810.

Soares, R. d. C. M., Mattos, L. R., & Raposo, L. M. (2020). Risk factors for hospitalization and mortality due to COVID-19 in Espírito Santo State, Brazil. *The American journal of tropical medicine and hygiene*, *103*(3), 1184.

Sokat, K. Y., & Altay, N. (2021). Serving vulnerable populations under the threat of epidemics and pandemics. *Journal of Humanitarian Logistics and Supply Chain Management*.

Speakman, E. M., Burris, S., & Coker, R. (2017). Pandemic legislation in the European Union: Fit for purpose? The need for a systematic comparison of national laws. *Health Policy*, *121*(10), 1021-1024.

SPI-B. (2020). Public Health Messaging for Communities from Different Cultural Backgrounds. In.

Spieker, M. (2021). Misguided Triage Ethics: Chances of Survival and Risks of Dying in the Coronavirus Pandemic. *Journal of Markets and Morality*, *24*(1).

Spiritus-Beerden, E., Verelst, A., Devlieger, I., Langer Primdahl, N., Botelho Guedes, F., Chiarenza, A., . . . Gaspar de Matos, M. (2021). Mental health of refugees and migrants during the COVID-19 pandemic: The role of experienced discrimination and daily stressors. *International Journal of Environmental Research and Public Health*, *18*(12), 6354.

Steele, D., & Duthie, K. (2021). Ethics of resource allocation in a public health emergency context. Healthcare Management Forum,

The Health Foundation. (2021). The forgotten crisis: exploring the disproportionate impact of the pandemic on disabled people. In.

The Independent Panel for Pandemic Preparedness and Response. (2021). COVID-19: Make it the Last Pandemic. In.

Theis, N., Campbell, N., De Leeuw, J., Owen, M., & Schenke, K. C. (2021). The effects of COVID-19 restrictions on physical activity and mental health of children and young adults with physical and/or intellectual disabilities. *Disability and Health Journal*, *14*(3), 101064.

Thomas, M., & Gordon, E. (2021). British Red Cross Covid-19 vulnerability index. In.

Thompson, A. K., Faith, K., Gibson, J. L., & Upshur, R. E. (2006). Pandemic influenza preparedness: an ethical framework to guide decision-making. *BMC medical ethics*, *7*(1), 1-11.

Truog, R. D., Mitchell, C., & Daley, G. Q. (2020). The toughest triage—allocating ventilators in a pandemic. *New England Journal of Medicine*, *382*(21), 1973-1975.

Truong, J., Bakshi, S., Wasim, A., Ahmad, M., & Majid, U. (2022). What factors promote vaccine hesitancy or acceptance during pandemics? A systematic review and thematic analysis. *Health promotion international*, *37*(1), daab105.

United Nations. (2020). Policy brief: a disability-inclusive response to COVID-19. *United Nation*, 1-18.

Uphoff, E. P., Lombardo, C., Johnston, G., Weeks, L., Rodgers, M., Dawson, S., Churchill, R. (2021). Mental health among healthcare workers and other vulnerable groups during the COVID-19 pandemic and other coronavirus outbreaks: A rapid systematic review. *PLoS One*, *16*(8), e0254821.

Upshur, R., Faith, K., Gibson, J., Thompson, A., Tracy, C., Wilson, K., & Singer, P. A. (2005). Ethical considerations for preparedness planning for pandemic influenza. *A report of the University of Toronto Joint Centre for Bioethics Pandemic Influenza Working Group*.

Valaine, L., Ancāne, G., Utināns, A., & Briģis, Ģ. (2021). Mental Health and Associated Demographic and Occupational Factors among Health Care Workers during the COVID-19 Pandemic in Latvia. *Medicina*, *57*(12), 1381.

van Der Schaar, M., Alaa, A. M., Floto, A., Gimson, A., Scholtes, S., Wood, A., Ercole, A. (2021). How artificial intelligence and machine learning can help healthcare systems respond to COVID-19. *Machine Learning*, *110*(1), 1-14.

Van Kolfschooten, H., & de Ruijter, A. (2020). COVID-19 and privacy in the European Union: A legal perspective on contact tracing. *Contemporary Security Policy*, *41*(3), 478-491.

Van Panhuis, W. G., Paul, P., Emerson, C., Grefenstette, J., Wilder, R., Herbst, A. J., Burke, D. S. (2014). A systematic review of barriers to data sharing in public health. *BMC public health*, *14*(1), 1-9.

Vanhaecht, K., Seys, D., Bruyneel, L., Cox, B., Kaesemans, G., Cloet, M., Lowet, K. (2021). COVID-19 is having a destructive impact on health-care workers' mental well-being. *International Journal for Quality in Health Care*, *33*(1), mzaa158.

Veiga-Seijo, R., Miranda-Duro, M. d. C., & Veiga-Seijo, S. (2022). Strategies and actions to enable meaningful family connections in nursing homes during the COVID-19: A Scoping Review. *Clinical Gerontologist*, *45*(1), 20-30.

Vergallo, G. M., Del Rio, A., Negro, F., & Zaami, S. (2022). COVID-19 vaccine mandates: What are the current European public perspectives. *Eur. Rev. Med. Pharmacol. Sci*, *26*, 643-652.

Villarosa, A. R., Ramjan, L. M., Maneze, D., & George, A. (2021). Conducting population health research during the COVID-19 pandemic: impacts and recommendations. *Sustainability*, *13*(6), 3320.

Vladisavljevic, A. (2020). Croatian Proposal to Track Self-Isolating Citizens Alarms Critics. https://balkaninsight.com/2020/03/25/croatian-proposal-to-track-self-isolating-citizens-alarms-critics/

Vogenberg, F. R. (2009). Predictive and prognostic models: implications for healthcare decision-making in a modern recession. *American health & drug benefits*, *2*(6), 218.

Voigt, P., & Von dem Bussche, A. (2017). The eu general data protection regulation (gdpr). *A Practical Guide, 1st Ed., Cham: Springer International Publishing*, *10*(3152676), 10-5555.

Wernly, B., Wernly, S., Magnano, A., & Paul, E. (2020). Cardiovascular health care and health literacy among immigrants in Europe: a review of challenges and opportunities during the COVID-19 pandemic. *Journal of Public Health*, 1-7.

World Health Organization. (2005a). *Outbreak communication: best practices for communicating with the public during an outbreak: report of the WHO expert consultation on outbreak communications held in Singapore, 21-23 September 2004*.
World Health Organization. (2005b). WHO checklist for influenza pandemic preparedness planning. In.
World Health Organization. (2007). *Ethical considerations in developing a public health response to pandemic influenza*.
World Health Organization. (2017). WHO guidelines on ethical issues in public health surveillance.
World Health Organization. (2020a). Ethical considerations to guide the use of digital proximity tracking technologies for COVID-19 contact tracing.
World Health Organization. (2020b). Risk communication and community engagement (RCCE) action plan guidance COVID-19 preparedness and response.
World Health Organization. (2021a). Forum on Law and COVID-19: Strengthening Legal Preparedness and Response for the Future, Virtual meeting, 3-4 November 2021: meeting report.
WHO. (2021b). International Health Regulations. In.
World Health Organization. (2021c). WHO competency framework: building a response workforce to manage infodemics.
World Health Organization. (2022a). COVID-19 and mandatory vaccination: ethical considerations: policy brief, 30 May 2022. In *COVID-19 and mandatory vaccination: ethical considerations: policy brief, 30 May 2022*.
World Health Organization. (2022b). *WHO report shows poorer health outcomes for many vulnerable refugees and migrants*. https://www.who.int/news/item/20-07-2022-who-report-shows-poorer-health-outcomes-for-many-vulnerable-refugees-and-migrants
Wild, A., Kunstler, B., Goodwin, D., Onyala, S., Zhang, L., Kufi, M., Asthana, M. (2021). Communicating COVID-19 health information to culturally and linguistically diverse communities: insights from a participatory research collaboration. *Public Health Res Pract*, *31*(1), 38-51.
Williams, S. N., Armitage, C. J., Tampe, T., & Dienes, K. (2021). Public attitudes towards COVID-19 contact tracing apps: A UK-based focus group study. *Health Expectations*, *24*(2), 377-385.
Williamson, E. J., McDonald, H. I., Bhaskaran, K., Walker, A. J., Bacon, S., Davy, S., Ramsay, M. (2021). Risks of covid-19 hospital admission and death for people with learning disability: population based cohort study using the OpenSAFELY platform. *bmj*, *374*.
Williamson, V., Stevelink, S. A., & Greenberg, N. (2018). Occupational moral injury and mental health: systematic review and meta-analysis. *The British Journal of Psychiatry*, *212*(6), 339-346.
Wilson, J., Heinsch, M., Betts, D., Booth, D., & Kay-Lambkin, F. (2021). Barriers and facilitators to the use of e-health by older adults: a scoping review. *BMC Public Health*, *21*(1), 1-12.
Wilson, K., Halabi, S., & Gostin, L. O. (2020). The International Health Regulations (2005), the threat of populism and the COVID-19 pandemic. *Globalization and Health*, *16*(1), 1-4.
Wu, B. (2020). Social isolation and loneliness among older adults in the context of COVID-19: a global challenge. *Global health research and policy*, *5*(1), 1-3.
Wylie, C. (2022) 'No payments' for unvaccinated healthcare staff sacked in mandatory jab plans. Available at: https://www.independent.co.uk/news/uk/nhs-stephen-powis-royal-college-of-midwives-vaccination-health-service-journal-b1993545.html
Wynants, L., Van Calster, B., Collins, G. S., Riley, R. D., Heinze, G., Schuit, E., Debray, T. P. (2020). Prediction models for diagnosis and prognosis of covid-19: systematic review and critical appraisal. *bmj*, *369*.
Yang, C.-c., Tsai, J.-Y., & Pan, S. (2020). Discrimination and well-being among Asians/Asian Americans during COVID-19: The role of social media. *Cyberpsychology, behavior, and social networking*, *23*(12), 865-870.
Yashadhana, A., Derbas, A., Biles, J., & Grant, J. (2022). Pandemic-related racial discrimination and its health impact among non-Indigenous racially minoritized peoples in high-income contexts: a systematic review. *Health Promotion International*, *37*(2), daab144.
Yearby, R. (2021). Reifying racism in the COVID-19 pandemic response. *The American Journal of Bioethics*, *21*(3), 75-78.
Yip, J. Y.-C. (2021). Healthcare resource allocation in the COVID-19 pandemic: Ethical considerations from the perspective of distributive justice within public health. *Public Health in Practice*, *2*, 100111.

Zhao, I. Y., Ma, Y. X., Yu, M. W. C., Liu, J., Dong, W. N., Pang, Q., Wong, C. W. W. (2021). Ethics, Integrity, and Retributions of Digital Detection Surveillance Systems for Infectious Diseases: Systematic Literature Review. *Journal of medical Internet research*, *23*(10), e32328.

Zheng, G., Jimba, M., & Wakai, S. (2005). Exploratory study on psychosocial impact of the severe acute respiratory syndrome (SARS) outbreak on Chinese students living in Japan. *Asia Pacific Journal of Public Health*, *17*(2), 124-129.

Zheng, Z., Peng, F., Xu, B., Zhao, J., Liu, H., Peng, J., Liu, S. (2020). Risk factors of critical & mortal COVID-19 cases: A systematic literature review and meta-analysis. *Journal of infection*, *81*(2), e16-e25.