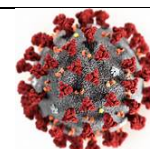


National COVID-19 Science Task Force (NCS-TF)



Type of document: ELSI Report	
In response to request from: name, institution, contact details	Date of request: dd/mm/2020
Expert groups involved: Ethical, legal, social list one or several	Date of response: dd/mm/2020
Contact person: samia.hurst@unige.ch , 0794743146	
Comment on planned updates :	
Title: Ethical, legal, and social benchmarks for transition strategies.	
Summary of request/problem : The Scientific task force was tasked with examining transition strategies and proposing scenarios. The Ethical, legal, and social group examined benchmarks applicable to any transition strategy.	
<p>Executive summary: Based on the Toronto framework developed following the SARS epidemic, as well as on the main ethical, legal, and social issues identified by the ELSI group, the main benchmarks for transition strategies are the protection of personal rights, the protection of the public from harm, equity and solidarity, principles of the rule of law, and trustworthiness and communication.</p> <p>Based on this approach, recommended benchmarks for transition strategies are: ongoing examination of the available data, including information on the socio-economic profile of new cases and deaths; a reporting system to observe the effects of the pandemic and of pandemic response policies on different populations; mechanisms for dispute resolution and rights of appeal for all restrictive measures; financial provisions and support services for those affected by restrictive measures, and for those whose work places them in the way of harm for the public good; efforts to mainstream advance care planning; measures to actively avoid direct and indirect discrimination in restrictive measures, their withdrawal, and possible reimplementations; protection of the right to an education; integration of democracy and federalism in transition scenarios; procedural guarantees and appropriate legal bases for limitations of personal rights; and a commitment to public information and trustworthiness.</p>	
Main text	
<p>Following the SARS epidemic, the Toronto group developed a framework to address ethical issues in pandemic response(1). This framework includes 10 substantive values: individual liberty, protection of the public from harm, proportionality, privacy, duty to provide care, equity, reciprocity, solidarity, trust, and stewardship or the duty for those entrusted with governance roles to be guided by the public interest. It also includes five procedural values:</p> <ol style="list-style-type: none"> 1. Decisions should be based on reasons (i.e., evidence, principles, and values) that stakeholders can agree are relevant to meeting health needs in a pandemic crisis. The decisions should be made by people who are credible and accountable. 	

2. The process by which decisions are made must be **open** to scrutiny, and the basis upon which decisions are made should be publicly accessible.
3. Decisions should be **inclusive** and made explicitly with stakeholder views in mind, there should be opportunities to engage stakeholders in the decision-making process.
4. Decisions should be **responsive**. There should be opportunities to revisit and revise decisions as new information emerges throughout the crisis. There should be mechanisms to address disputes and complaints.
5. There should be mechanisms in place to ensure that decision makers are **answerable for their actions and inactions**. Defense of actions and inactions should be grounded in the other ethical values proposed above.

These substantial and procedural values apply when implementing, but also when adapting or lifting public health measures.

From a legal standpoint, the lifting of emergency measures is not only a policy choice but a legal duty enshrined in the constitution and in international public law. This is particularly relevant for all measures infringing upon fundamental rights. All limitations of individual rights and freedoms must be based on written and published law, serve overriding public interests or the protection of fundamental rights of others, and be proportionate. As soon as such far-reaching measures are not necessary anymore, the government is obliged to adjust the restrictions.

These values and principles inform the recommendations presented here. The main benchmarks are the protection of personal rights, the protection of the public from harm, equity and solidarity, principles of the rule of law, and trustworthiness and communication. Recommendations are outlined at the end of the document.

Protection of personal rights

In designing a transition scenario, the search for less intrusive and more equal measures in all human rights fields must continue on an ongoing basis, especially regarding the duty to respect, protect and fulfill the rights to: personal freedoms, freedom of assembly; equality by the law and before the law, direct and - more importantly - indirect discrimination; right to basic education; special protection of children and young people; economic freedoms; religious freedoms ; privacy and family life. For each of the restrictions, the specific public interest justifying the restriction must be clarified. Only with a clearly defined public interest in mind can proportionality tests be made in a meaningful way. Any measure currently not passing the proportionality test should be a priority for correction.

Since one of the goals in designing a transition strategy is to avoid overwhelm of health system structures, it is particularly important to ensure that those individuals who would not want to be admitted to intensive care should have the opportunity to state this in an advance directive. Information regarding the medical management and prognosis of COVID-19 in different types of cases should be provided to health professionals and the

general public in order to mainstream support for advance care planning. The SAMW directives on Advance directives are an important resource here (2).

The right to education needs to be fully implemented. All children have a rights to free and *adequate* basic education that is *available to all children* (3). Pre-primary and primary education in distance learning is not sustainable and negatively affects the equality of chances. Primary and lower secondary schools should have priority over post-obligatory and tertiary education, where students are better able to learn online. Distance learning for high-risk group and tertiary education students should ensure equal access for disabled and low-income students.

Protection of the public from harm

It is not only safety from COVID-19 that should be equally protected, but access as much as feasible to all the components of a good life during a pandemic and during pandemic response.

Any transition scenario must identify benchmarks for loosening, but also for reinstating restrictive measures in order to protect the public from harm. It also requires compliance with the measures that are maintained. This requires eliminating or at least substantially reducing any obstacles that could prevent individuals from adhering to public measures. No one should continue working simply because there is no alternative in place for material survival. No one should work without protection for lack of it. No one should refrain from seeking diagnosis and medical care based on out-of-pocket payments. Measures taken to eliminate these obstacles must be publicized.

Individuals who become ill should be able to protect their families. Personal protective equipment should be available to family caregivers, and solutions for isolation outside the home should exist for those living in close quarters with particularly vulnerable individuals.

Any transition scenario must allow relevant actors (schools, hospitals, etc.) sufficient time to adjust to new measures while being able to guarantee the special protective measure that most likely will remain in effect (hygiene standards, social distancing, public gatherings etc.).

Any transition scenario is likely to include ongoing change and could require new confinement periods. These should be anticipated and appropriate preparation measures implemented.

Equity and solidarity

Any transition scenario must respect the principle of equality, not only formally but also substantially. There is a duty on all state authorities to prevent direct and also indirect (de facto) discrimination. This includes a duty to take special measures to equalize, and actively alleviate situations where some are disadvantaged. This is particularly important

when populations are placed at risk of being disadvantaged by the measures imposed upon them in pandemic response.

The 'public' or the 'population' is typically thought as a homogenous entity, while it is constituted of a large diversity of social groups having specific needs, preoccupations, risks associated with the virus. The anthropological literature emphasizes the importance of 'community' participation in the context of low and middle income countries (4), however the same holds for high income countries where 'one size fits all' strategies do not meet the diversity of needs and issues.

There is a very large variation in the (material, spatial, cognitive, etc) resources individuals have to handle the confinement and the transition period. The needs and preoccupations of the most vulnerable groups need to be specifically addressed. They include those more at risk of contracting the disease, and those more at risk of being adversely affected by containment measures. For example, low-income families and individuals, people in institutions, (undocumented) migrants, persons in jobs where telework is not possible, family caregivers, the homeless, disabled, allophone, or travelers.

Since pandemic response measures can actively disadvantage populations, there is a particular duty of the state to limit and compensate such disadvantages. In imposing burdens on persons and groups for the common good, collectivities acquire duties towards these persons and groups.

Principles of the rule of law

Even in times of emergency, exceptions need to take into account principles essential to the legal order (legality, legal certainty, prevention of abuse and misuse of power, access to justice etc.).

Significant restrictions of fundamental rights must normally have their bases in a law established by parliament. The emergency ordinances made by the executive must be submitted to parliament as soon as possible, as their legitimacy is fading over time. The federal assembly (and cantonal parliaments) should be allowed to amend their rules of procedures in a way allowing them to work.

Current measures are a “derogation in time of emergency” of the European Convention of Human Rights; a High Contracting Party is bound to “keep the Secretary General of the Council of Europe fully informed of the measures it has taken and the reasons therefor”, and of the time at which “such measures have ceased to operate and the provisions of the Convention are again being fully executed.” (5)

If there should be “test, trace and quarantine” component to a transition strategy, the quarantine must be organized in a human rights perspective. If quarantine is organized in a way constituting a deprivation of liberty (“house arrest” for several days), all the special

procedural guarantees including “the right to be notified without delay and in a language they can understand of the reasons for their detention and of their rights”, “the opportunity to exercise their rights, in particular, the right to have their next-of-kin informed” and “the right to have recourse to a court at any time” must be respected (6). These guarantees are considered “sacrosanct”, they cannot suffer any limitation, even in case of an emergency. Similar guarantees can be found in Art. 5 European Convention of Human Rights, generally taking primacy over contradicting national law. Courts would have to be prepared to deal with these cases speedily. If quarantine does not constitute a deprivation of liberty but “only” a limitation of personal freedom (7), the strict procedural rules cited above do not apply. But the limitation of freedom would still have to be based on law, limited to the strictly necessary, be considerate of vulnerabilities and special needs and capable of being challenge in court.

Given the novelty of the use of digital technologies to conduct disease surveillance (and surveillance of individual/population movement), governance frameworks are likely to be incomplete and this will need to be addressed. The National Advisory Commission on Biomedical Ethics’ position on digital contact tracing is an important resource here (8). Democratic review or control of this data should also be implemented. This could be done by existing bodies, such as parliament or the courts.

Trustworthiness and communication

Navigating through transition requires a commitment to share publicly as much information as possible (while respecting privacy of individuals and other justified exceptions) on key aspects of the evolution of the epidemic and the broader societal impacts of response measures. This includes not only numbers of confirmed cases and deaths, but also (as feasible, at federal level, and disaggregated by sex and age whenever possible):

- total number of tests performed and positive rate; false negatives and positives rates will also be important if roll-out of imperfect serological testing is envisaged, to help the public understand and accept;
- number of healthcare workers infected;
- total hospitalizations and ICU occupancy, as well as remaining unused capacity (providing a picture of severe and critical cases, disaggregated by sex and age);
- to the extent possible: socioeconomic data that may help shed light on whether certain groups (beyond sex and age) are more vulnerable to infection or progressing to severe/critical illness, e.g. poor, certain workers (including but not limited to healthcare professions), irregular (immigrants, homeless, mentally ill);
- The degree of knowledge and uncertainty regarding specific measures (e.g. masks).

Explanations should also be provided on the following aspects:

- It is important to explain the **reasons** for the implementation, withdrawal, or re-implementation of measures, especially as regards any elements on which the Swiss approach **differs significantly** from other similar countries or WHO guidance.

Variations in approaches are justified, given that no single country has all the answers and approaches need to be adapted to national/local contexts. But such variation raises questions that should be answered.

- Any **prioritization** is bound to be criticized, and needs to be justified and explained.
- If clear **benchmarks** can be established, eg 300 new daily confirmed cases, it is important to provide a full explanation for the benchmark.
- Areas of **uncertainty** and insufficient evidence are inevitable. Explaining them can help the public to understand and accept the need for flexibility, changes in policies as knowledge grows, situation evolves.

Principles of risk and crisis communication emphasize the importance of a 2-way communication, in other words mechanisms to listen to people's preoccupations should be put in place. This allows for bringing up issues that might have been forgotten so far. Such strategies of two-way communication should also be considered in specific environment, such as for example the workplace, to respond to local needs and preoccupations.

Protecting trust, which must be a key aspect of pandemic response, can best be done through a **trustworthiness first, then communication** framework. Trust is given when we believe that an agent will do a specific thing in a manner that is competent, reliable, and honest (9). Rather than complete transparency, which is never achievable, it is visibly truthful communication on the goals and actions taken as well as on the level of competence, reliability, and honesty that can be expected, that form the basis of trust.

Recommendations

1. Ongoing examination of the available data is needed in order to define points at which measures should be eased or lifted, or tightened.
 - These data should include information on the socio-economic profile of new cases and deaths.
 - A reporting system should be put in place to observe the effects of the pandemic and of pandemic response policies on different populations on an ongoing basis. In addition to data gathering on new cases and deaths, feedback from a range of stakeholders including trade unions, local associations, businesses, human rights organizations (humanrights.ch for example) and citizens should be facilitated and systems put in place to enable it.
2. Protocols for implementation of restrictive measures should be founded upon the principles of proportionality and least restrictive means (which includes time limitations), and should build in safeguards such as mechanisms for dispute resolution and the right of appeal.

3. Measures and processes should be implemented to guarantee financial and material provisions as well as support services to individuals and/or communities affected by restrictive measures, such as quarantine orders.
 - Support should be available to help those who are isolated, quarantined, or confined. When measures are eased, protection of those who return to work should be implemented strictly and in all areas.
 - Protection from professional and financial repercussions should be in place not only for patients who isolate, but for contacts who quarantine and for all persons advised to stay home and who cannot telework.
 - Those whose work is essential and places them in the way of harm should be guaranteed the means to protect themselves and their families, access to care, and access to disability insurance and assistance in bearing funeral costs should they become disabled or die as a result of contracting the disease in their line of work. These measures should remain in place when restrictive measures are eased.
4. To assist in preventing overwhelm of health system structures, information regarding the medical management and prognosis of COVID-19 in different types of cases should be provided to health professionals and the general public and efforts to support advance care planning should be mainstreamed.
5. Direct and indirect discrimination should be actively avoided.
 - Vulnerable persons (at risk of violence, living in precarious conditions, single parents, persons with disabilities, children with learning difficulties), should profit first if possible.
 - In addition to general communication through the media, communication should make use of multiple languages as well as go through multipliers addressing specific groups.
 - Any protection measure (eg masks in crowded areas or in the public sphere) should be implemented along with special measures to ensure that they are available to all.
 - Strategies should include protections against stigmatization and to safeguard the privacy of individuals and/or communities particularly affected by quarantine or other restrictive measures. Differential protections for populations that are immune or non-immune, for example, are at high risk of translating into two-tiered citizenship and this needs to be avoided.
 - Testing results must not result in unequal treatment; it would be problematic if people tested positively were to be exposed to higher (and unknown) risks, treated differently at the workplace, or systematically used for military and civil service without appropriate justification and legal protections.
 - Non-COVID19 patients should be treated by the health system on an equal basis, delayed interventions should be scheduled as soon as the situation allows, without waiting for the end of the pandemic.

- Specific interventions should target the risks associated with isolation and immobilization in the >65 population: put in place « safe spaces » for the elderly (clubs, gym classes, walks); support local shopping options, without queueing, or maintain provision by volunteers while allowing some contacts (move away from the zero contact of dropping bags behind a door and no interactions between volunteers and elderly people) ; allow older persons who are willing to take the risk of becoming infected to not quarantine themselves from persons in low-risk groups (for example grandchildren).
6. The right to education needs to be fully implemented. Primary and lower secondary schools should have priority over post-obligatory and tertiary education, where students are better able to learn online. Distance learning for high-risk group and tertiary education students should ensure equal access for disabled and low-income students.
 7. Transition scenarios should address democracy and federalism. They should specify the duration for which public votes are cancelled, and how long the halt for the collection of signatures for initiatives and referendums should be upheld, and integrate a strategy enabling parliament to resume as soon as possible. The autonomy of the cantons to take their own decision must be reestablished as soon as possible and their participation in federal decision-making should be strengthened.
 8. Limitations of personal rights require the appropriate legal bases.
 - Any quarantine organized in a way constituting a deprivation of liberty must respect the procedural guarantees contained in Art. 31 of the Federal Constitution. Special care must be taken to provide persons deprived of liberty with all basic means.
 - Governance frameworks for the use of digital technologies, including mechanisms for democratic review or control, will need to be established.
 - Current measures are a “derogation in time of emergency” of the European Convention of Human Rights: the Secretary General of the Council of Europe must be kept fully informed of the measures taken and their reasons, as well as of the time at which these measures have ceased to operate and the provisions of the Convention are again being fully executed”.
 9. Navigating through transition strategies requires a commitment to share publicly as much information as possible (while respecting privacy of individuals and other justified exceptions) on key aspects of the evolution of the epidemic and the broader societal impacts of response measures. Explanations should be provided on the rationale for the implementation, withdrawal, or re-implementation of measures ; on the reasons for any prioritizations or benchmarks, as well as on areas of uncertainty.

Unresolved issues

1. Who is particularly vulnerable to being disadvantaged by pandemic response measures? Our team can work on this.
2. How to establish a reporting system to observe the effects of the pandemic and of pandemic response policies on different populations on an ongoing basis? Our team can collaborate in such an effort.

References

1. The University of Toronto Joint Centre for Bioethics Pandemic Influenza Working Group : « Stand on guard for thee; Ethical considerations in preparedness planning for pandemic influenza” November 2005
2. Swiss Academy of Medical Sciences : “Advance directives” 2009, updated 2013
3. Art. 19 and 62 of the Constitution
4. See for example Wilkinson et al. 2017 <http://dx.doi.org/10.1098/rstb.2016.0305>
5. Art.15 European Convention of Human Rights on “Derogation in time of emergency”
6. Art. 31 Federal Constitution
7. Art. 10 para 2 Federal Constitution
8. Nationale Ethikkommission im Bereich der Humanmedizin NEK : “Contact Tracing” N°33/2020
9. O’Neill Onora, A Question of Trust. Reith lectures 2002. <http://www.bbc.co.uk/radio4/reith2002/>

Appendices