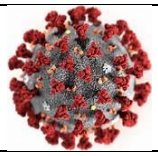
National COVID-19 Science Task Force (NCS-TF)



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Title: Continued confinement of those most vulnerable to COVID19

Summary of request/problem : The Scientific task force was tasked with refining aspects of possible transition strategies. The Ethical, legal, and social group examined aspects associated with the continued confinement of those most vulnerable to COVID19

Executive summary: In our policy brief on ELSI benchmarks for transition strategies, we had stated that:

"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 grand-children). »

In this policy brief, we more systematically examine requirements for the protection of vulnerable persons, the situation in institutions, legal implications, requirements to sustain vulnerable persons, and self-determination. We recommend the following:

1) Confinement cannot be the only measure in place to protect vulnerable persons. Protections are needed to enable participation in the public sphere and the exercise of rights for persons particularly vulnerable to COVID19.
2) Many long-term care homes have currently banned visits from residents' next of kin and legal representatives. This situation must be corrected and solutions developed to enable contacts with these persons while still limiting the risk of contagion. Strategies enabling this should be shared among institutions in order to facilitate the diffusion of successful processes. Concepts of care compatible with accepted standards of care (both curative and palliative) must exist on site. These institutions have to be staffed with adequate resources to fulfil these tasks. Those confined in long-term care institutions should also continue even in confinement to have access to some forms of social contacts, as well daylight, sun and fresh air daily similar to the rights of persons under detention. Residents of institutions have the same rights to clear, loyal, and truthful information regarding the pandemic situation and the reasons why measures are in place, as the rest of the population. The authorities must monitor these measures.

3) Vulnerable persons should retain the choice to place themselves at risk, as long as they do not impose risks on others. Continued confinement should be a recommendation and a right, not a duty or an obligation.
4) Vulnerable persons who choose to remain in confinement should be protected against loss of their jobs or income, and against the risk of discrimination in the labor market. If people vulnerable to Coronavirus are allowed to opt out of working obligations, the duty of the employer to pay wages must be limited. After this period, social security should step in. If confinement persists, retraining through invalidity insurance may have to be considered in these cases. As the elderly may place themselves at risk if they take care of their grand-children, free access to child-care for parents should also be part of a protection strategy.
5) Risk and crisis communication stresses the importance to listen to the people and to set up participatory approaches. Associations and lobbies representing the views of groups of those particularly vulnerable to COVID19 (both the elderly and those with diseases placing them at particular risk) should be consulted. Most vulnerable persons are autonomous, competent and should be allowed to voice their own opinion.

In this brief, we examine issues associated with the continued confinement of those considered vulnerable to COVID19: the elderly, but also those with chronic diseases and risk factors. Policies for deconfinement increasingly assume that these persons will remain confined even when others will not. This could last quite a long time, and for some this could mean that they will remain in confinement for the rest of their lives.

In our policy brief on ELSI benchmarks for transition strategies, we had stated that:

"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 grand-children). »

When discussing the continued confinement of those at particular risk of dying of COVID19, the elderly (>65) and those with chronic conditions "especially high blood pressure, diabetes, cardiovascular disorders, chronic respiratory disorders, disorders and therapies which weaken the immune system, and cancer" are the usual target group. Defining entire categories is, however, problematic. Considering all people aged over 65, for example, as vulnerable seems overly simplistic. Social scientists have regretted that it has long been assumed that those over 65 represent a homogeneous category of those who had retired. To the contrary, people over 65 represent a very heterogeneous category, with contrasted socioeconomic groups, family circumstances and health conditions. The over 65 present contrasted health conditions. The distinction between the 3rd and 4th age has been coined to differentiate those who are still in good health and active, and those who later in old age become fragile and dependent (Laslett 1991). The same applies to persons with health conditions placing them at risk of dying should they contract COVID19. Protections need to take this into account. From a legal standpoint, the strict

age limit is problematic as well. According to the constitution (and international law), age discrimination is prohibited. Strict age limits can be constitutional (despite this prohibition) but only if there are based on highly convincing reasons (e.g. age limits for marriages). The fact that health risks generally tend to increase at the age of 65 years is insufficient to apply strict age limits. Healthy 66 year old people cannot be bound by the same legal rules as people with multiple additional risk factors, without violating the principle of equality. People have a right to be treated equally if they are equal regarding the matters at stake, and they have a right to differentiated treatment if there are relevant differences. The diseases bringing people into the group of vulnerable people must also be further clarified. The current list is very vague and explicitly not exhaustive. Here again, further differentiation is crucial.

There are three reasons to maintain confinement of those particularly vulnerable to dying of COVID-19: protecting them as equally worthy of life in a situation where their life is more at risk, protecting the health system from overwhelm at a time when they may become ill in numbers too great to treat simultaneously, and protecting others in case the particularly vulnerable are also particularly likely to pass on the disease to others.

Regarding the first reason, protection of vulnerable persons themselves cannot justify compelled confinement if they are the ones at risk. After all, they should have the right to protection, but should nevertheless be able to choose freely whether or not to place themselves at risk. Regarding the third reason, the available evidence does not point to a heightened risk of contagion on the part of those most vulnerable to dying of COVID19. An exception could apply in long-term care institutions, where the number of people living in close quarters could pose a risk and this could justify continued confinement if it was expected to be protecting. Outside long-term care facilities, however, the only justification to confine these persons for the protection of others, then, could come from the fact that vulnerable people are more likely to need special/intensive care. If there should be a shortage of special/intensive care, it could be conceivable to confine those people more strictly who are most likely to be in need of it. This justification exists when intensive care structures are at risk of becoming overwhelmed, but ceases to exist when the epidemic is sufficiently controlled to avoid this. Even while it exists, however, this consideration needs to be balanced with others.

Protecting the vulnerable

Confinement was accepted on the basis of the requirement to protect life and health, in particular for those who are more vulnerable to dying of COVID19. This requirement applies more broadly. Special accommodations need to be made for vulnerable individuals during court and administrative procedures, including asylum procedures, protective refuge should be available for their family members who become ill with COVID19 and do not require hospitalization, vulnerable persons should be considered for early release from prison. When protective measures, such as masks, are recommended, they should be free of charge for vulnerable individuals. As the elderly may place themselves at risk if they take care of their grand-children, free access to child-care for parents should also be part of a protection strategy. Those who are vulnerable are also listed among the populations which should receive priority for a vaccine once it becomes available by the Swiss pandemic plan (SFOPH 2018). Protection should not be a privilege dependent on income for vulnerable persons, but a right.

Risks are also associated with confinement itself. Early signs of the adverse effects of confinement are being observed by professionals, references have been made to the 'failure to thrive', a condition which includes four aspects: weight loss, decreased appetite, poor nutrition, and

inactivity (Robertson & Montagnini 2004). It can be expected that long term confinement will lead to an increased number of deaths as a result of isolation, lack of exercise, limited access to basic resources among the elderly. The balance of risks is thus uncertain. Protection against exposure to the virus comes at the cost of other components of health taking into consideration the balance between biological, psychological and social factors (Engel 1977). In exploring components of a good life, the influential capabilities approach lists: life, bodily health, bodily integrity, senses, imagination and thought, emotions, practical reason, affiliation including social interaction and the social bases of self-respect, contact to other species and the natural world, play, and control over one's political and material environment (Nussbaum 2000). Particular attention should thus be paid to maintaining equal protection of life in all circumstances, but also equal political rights, equal possibilities for social interaction, for play, and most importantly perhaps equal access to the social bases of self-respect: the image mirrored back to us by society, which constitutes an important part of our assessment of our own worth. Social distancing should mean neither social exclusion, nor social devaluing. Robeyns (2016) proposed the addition of sensory comfort, communication, being understood, being loved and receiving attention, several of which are at risk during the present confinement, especially in populations unaccustomed to communicating through digital technologies. In the absence of sustained communication, those who remain confined must rely entirely on others to tell their story and cannot sustain their narrative identity (Hurst, 2020 and Lindemann, 2014).

Since there are several different populations of individuals vulnerable to COVID19, no single trade-off between these components can be described for them all. Decisions about confinement of the vulnerable should include their needs and own definition of the situation, either directly or through representation groups such as, for example *Pro Senectute* for the elderly. Their perceptions of risks are likely to be different from those of other segments of the population, and from those of health professionals. Concurrent perceptions of risks thus need to be taken into account (this holds for all vulnerable groups), especially in a context characterized by high uncertainty and in which trade-offs might be difficult to calculate.

Protection should be a right not a duty. Individuals vulnerable to severe illness from SARS-COV-2 should be afforded the same liberties and personal choices as others, and these include placing themselves at risk. If vulnerable people are not systematically more likely to spread SARS-COV-2, it does not seem justified to reduce their freedom to choose whether or not they remain confined.

The situation of institutions

Persons who are vulnerable to dying of COVID19 and who are also residents in institutions can become at greater risk of contracting the disease due to their circumstances. Special protections ought to extend to them. Accommodations, including adequate personal protective equipment for staff and where appropriate for residents, should be put in place to decrease this risk.

In many places, protections have included bans on visits from the outside. This has had the unfortunate consequence of making residents inaccessible to their family, and also to their advocates and legal representatives. This situation must be corrected and solutions developed to enable contacts with these persons while still limiting the risk of contagion. Strategies enabling this should be shared among institutions in order to facilitate the diffusion of successful processes. Residents who are capable of decision-making must also be allowed to take risks if they so choose, as long as they do not endanger others.

Currently, explicit provisions exist in certain cases to discourage, restrict or even prevent the referral of residents from nursing home to hospital. This is a striking inequality if the actual place of care (and not the medical condition and needs) is the sole condition for admission. In any case, concepts of care compatible with accepted standards of care (both curative and palliative) must exist on site. Legal representatives must be actively involved in the case of lack of mental capacity. The possibility to contact the guardianship authorities and "see behind the curtains" of those confined in institutions must be proactively granted by these institutions. The authorities must monitor these measures. These institutions have to be staffed with adequate resources to fulfil this task, which is assigned them by the civil code.

Those confined in long-term care institutions should also continue even in confinement to have access to some forms of social contacts, as well as daylight, sun and fresh air daily similar to the rights of persons under detention. Especially if conditions have to change in order to decrease the risk of contagion, accommodations need to be made to enable the maintenance and continuation of people's meaningful daily activities, their "engagements" that have existential values. Many of these activities have complex functions: physical activity, support imagination, social and affective life, and sense-making.

Finally, residents of institutions have the same rights to clear, loyal, and truthful information regarding the pandemic situation and the reasons why measures are in place, as the rest of the population. This will require active engagement by the staff in order to overcome sensory and cognitive impairments when they are present, and to inform residents on measures taken by the institution itself and their reasons.

Legal implications

If confinement for specific groups should continue, there would be a great need for clarification:
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- Is the confinement a government recommendation or a legal obligation?
- What exactly does confinement involve? What are confined people allowed or not allowed to do?
- Who exactly is concerned? Is there one category of vulnerable persons or several? Who decides whether a person falls in the category or not and how can such a decision be challenged?
- What is the situation of people living in the same household with confined people?

Legal implications of an obligation

A legal obligation would involve very numerous and serious legal issues. Some of the legal problems involved are so great that we would qualify them as insurmountable. As the restrictions to fundamental rights would be severe, (1) the legal basis would have to be a law made by parliament (federal or cantonal - depending on competencies), (2) be based on an overriding public interest (which cannot be to protect vulnerable people against their will) and (3) be proportionate. Human rights limitations cannot be justified by the political will of protecting people from themselves. Persons who are capable of judgement enjoy the right to self-

determination which includes the right to take unreasonable and risky decisions. Any person capable of judgement has a right to die (protected by the constitution and the European Convention of Human Rights), a fortiori, any person, vulnerable or not, has the right to accept health risks. The right to life is a right, not a duty; the same goes for the right to health. Any containment policy justified by the idea of protecting vulnerable people from unreasonable decisions they might take, would hence violate the constitution and international law.

Mandatory confinement could only be justified in three situations:

1. The vulnerable person is **not capable of decision-making** (because she suffers from dementia, depression, etc.). In such a situation, the civil law rules on protection of adults and agency apply.
2. The person fulfills the requirements of a mandatory care accommodation (Art. 426 Civil Code)
3. There is an overriding public interest other than protecting the confined person, such as a risk to the rights and freedoms of other people or a need to protect the overall health system from becoming dysfunctional. In our view, this is the only public interest on which confinement policies could be based.

Even if one of these situations is given, all confinement measures would still have to be proportionate. Even a person incapable of decision-making could thus not be confined without ensuring that this measure is necessary to protect her and that the confinement is reasonable given her overall situation. Family members or legal representatives would have to take the necessary decisions. If the confinement is established to protect the overall health system, only a flexible system (reacting to the situation in the hospitals, to the number of available intensive care beds and ventilators) would be proportionate. In addition, it would not be proportionate - and hence not be constitutional - to confine vulnerable people who have renounced the use of intensive care/ventilators in an Advance directive.

The ECHR case law is quite clear on this issue (deprivation of liberty according to art. 5 para. 1 lit. e ECHR): “Taking the above principles into account, the Court finds that the essential criteria when assessing the “lawfulness” of the detention of a person “for the prevention of the spreading of infectious diseases” are whether the spreading of the infectious disease is dangerous to public health or safety, and whether detention of the person infected is the last resort in order to prevent the spreading of the disease, because less severe measures have been considered and found to be insufficient to safeguard the public interest. When these criteria are no longer fulfilled, the basis for the deprivation of liberty ceases to exist.” (ENHORN v. SWEDEN, N 44). Confinement measures can thus only be examined under the criteria of contributing to the prevention of the spreading of the virus and when this is the last resort.

The situation of mandatorily confined people would have to be determined in numerous ways, including work, social security, health services, family, social, and cultural life, use of political rights, use of religious rights, tenancy, etc. Appeals procedures would have to be in place. The government, severely limiting fundamental rights and freedoms, would have to take special responsibilities for all concerned people and be obliged to make best efforts in order to limit harm and to enable maximum human rights enjoyment. Such confinement could not take place at home without negating the entire aim, since others living with the confined individual could still transmit the virus outside the home.

Overall, then, a legal obligation for continued confinement of the vulnerable seems to entirely lack feasibility and justifications. We conclude that this path should not be pursued.

Legal implications of a recommendation

A government **recommendation** would raise very different questions than a legal obligation. As long as vulnerable people are not legally bound to stay at home, the government can use its soft power to protect specific groups and the health system. As long as people are free to follow or not follow a recommendation, freedom rights are not limited. The issuing of recommendations as such is thus not a legal problem. A recommendation may not be enforced, not even by soft measures.[1]

However, numerous questions would need to be clarified. What is the legal situation of vulnerable people deciding to follow the recommendation? And what would be the situation of people not following it? If negative legal (financial) consequences are attached to such a decision, a recommendation can turn into a de facto obligation. And this is to be prevented as it blurs rights and obligations into a non-transparent mixture.

Regarding labor law, and according to existing rules, the employer is obliged to allow persons at-risk to work from home. If their presence is indispensable, the employer must take necessary measures to protect this person. Still, a particularly vulnerable person may refuse to work if he or she considers the health risks to be too high. If then working at home or from the workplace is not possible, the employer must allow the person to stop working while continuing to pay wages.[2] This regulation, as it stands, is not fully clear (when is working from home or from the workplace "possible"?) . In addition, the individual employer can be overburdened by it. She or he can take all necessary measures at the workplace and the vulnerable person is still allowed to refuse to work. The refusal to work might be caused by the risks of commuting or the fear to endanger other vulnerable persons living in the same household, etc. The obligation of the employer to continue to pay wages is currently not limited - in contrast to the rules which would apply normally.

If people vulnerable to COVID19 are allowed to opt out of working obligations, the duty of the employer to pay wages would have to be limited in time as well. After this period, social security would have to step in. Otherwise, there is an (increased) risk that employers stop employing vulnerable people or terminate work contracts. The continued confinement would then further disadvantage vulnerable people in the labor market.

The situation of vulnerable persons without a work contract (self-employed or other) would also need to be clarified.

The effects on families and on child-care would have to be taken into account as well. 40% of all grand-parents take care of their grand-children weekly. Overall, they spend about 160 million hours a year looking after children. If there is a recommendation (or an obligation) not to do so, young families (and child-care institutions) will have to carry new burdens. These burdens would have to be collectively born, at least in part. If grand-parents are prevented from looking after children - they (and their families) would then be obliged to make special efforts to protect the health system in the interest of all and should not have to shoulder the financial costs of it.

[1] see the Canton of Ticino: ID papers may not be checked at the entrance of shops if staying at home of people above 65 is a recommendation, not a duty

[2] https://www.bag.admin.ch/bag/de/home/krankheiten/ausbrueche-epidemien-pandemien/aktuelle-ausbrueche-epidemien/novel-cov/massnahmen-des-bundes.html#797337129

Sustaining the vulnerable

What is our responsibility to take certain actions so that the more vulnerable can have more freedom to participate in social and public life, without exposing themselves to unacceptable levels of harm? Individual rights that are balanced with safety during a pandemic do not go away. Rather, they are balanced against the right to life and health during exceptional circumstances. When the situation is acute and leaves no time for measures other than confinement, this balance can be justified. When the situation persists for a longer time, however, providing safe spaces [3] and measures which re-enable the exercise of individual rights becomes possible. Societies are adapting to living with COVID19, and re-organizing many activities. This reorganization to re-enable life and the exercise of individual rights, then, needs to happen for everyone and not only for those who are professionally active and not particularly vulnerable to COVID19.

Examples could include reserved times in shops, museums, libraries, or cinemas, where fewer people would be allowed in at any one time so that those particularly vulnerable to dying of COVID19 could interact without placing themselves at risk. It could include safe transports for those at particular risk: as the lock down measures ease and more people move around, it will become more problematic for high-risk persons to go out (in order to get regular cancer treatment, for instance). In a situation where distance is being promoted, special measures aimed at re-establishing social ties will also be needed. And so on.

When assessing whether to do these things, it should be remembered that everyone's freedom is assisted and that this always has a cost. We have collectively invested in transportation infrastructure to allow us to come, go, earn a living, exercise our social and political rights. We need to invest in such facilitating institutions for the benefit of everyone, not of some only. Responding to the COVID19 pandemic has forced us to reorganize many aspects of our collective life. It should also force us to reorganize the possibilities for everyone to participate. Equal regard for the dignity of all persons, considered to be the basis for all fundamental rights by the Swiss constitution (art 7), would seem to require it.

Inevitably, however, trade-offs will arise. The question then becomes one of balancing the rights and interests of different groups against others. It seems unjust to disregard the rights of the 'vulnerable' or the 'non/less-vulnerable' entirely, meaning neither confinement of vulnerable groups nor total freedom to engage in any action by non/less-vulnerable groups is acceptable. This must be informed by science and public health principles, but ultimately these are decisions that must be made in a democratically legitimate manner.

Self-determination

From a risk management perspective, the COVID-19 pandemic does not appear as a riskier situation than many of the other – sometimes serious – health problems facing the elderly or those with chronic conditions. Where confinement aims to protect the vulnerable themselves, then, there is no justification to withhold the choice from them. If the epidemic can be sufficiently

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controlled, then an individual should have the right to decide how much risk they are willing to take. For many, the level of acceptable risk is above zero. The health system is there to care for those who become ill, in the same way that it cares for those who get into ski accidents or develop chronic illnesses linked to personal choices. A low-level, sustainable steady rate of cases may be inevitable, in the same way, a low-level, steady rate of car accidents happens every year, despite reasonable precautions by the state.

This means that it is important to distinguish situations where choices made by individuals actually harm others (for example, a resident in long-term care who insists on holding a birthday party with all the other residents and invite her family) from situations where these choices do not harm others (for example, a resident in long-term care who insists on receiving a visit from her 7-year-old grand-daughter, who can visit without crossing paths with anyone else).

It also means that taking away the choice wrongs the vulnerable in two distinct ways: first by limiting their self-determination, but also by sending the implicit message that vulnerable individuals are not competent to make their own decisions.

A prolonged confinement based on age will mean age segregation could reinforce current negative reactions towards those who do not follow the 'stay home' message. Messages advising for self-determination could undermine such stigmatization. They would also limit within family conflicts of younger generations being overprotective towards their parents and grandparents as a result of official messages.

Recommendations

1. Confinement cannot be the only measure in place to protect vulnerable persons. Protections are needed to enable participation in the public sphere and the exercise of rights for persons particularly vulnerable to COVID19.
2. Many long-term care homes have currently banned visits from residents' next of kin and legal representatives. This situation must be corrected and solutions developed to enable contacts with these persons while still limiting the risk of contagion. Strategies enabling this should be shared among institutions in order to facilitate the diffusion of successful processes. Concepts of care compatible with accepted standards of care (both curative and palliative) must exist on site. These institutions have to be staffed with adequate resources to fulfil these tasks. Those confined in long-term care institutions should also continue even in confinement to have access to some forms of social contacts, as well daylight, sun and fresh air daily similar to the rights of persons under detention. Residents of institutions have the same rights to clear, loyal, and truthful information regarding the pandemic situation and the reasons why measures are in place, as the rest of the population. The authorities must monitor these measures.
3. Vulnerable persons should retain the choice to place themselves at risk, as long as they do not impose risks on others. Continued confinement should be a recommendation and a right, not a duty or an obligation.
4. Vulnerable persons who choose to remain in confinement should be protected against loss of their jobs or income, and against the risk of discrimination in the labor market. If people vulnerable to Coronavirus are allowed to opt out of working obligations, the duty

of the employer to pay wages must be limited. After this period, social security should step in. If confinement persists, retraining through invalidity insurance may have to be considered in these cases. As the elderly may place themselves at risk if they take care of their grand-children, free access to child-care for parents should also be part of a protection strategy.

5. Risk and crisis communication stresses the importance to listen to the people and to set up participatory approaches. Associations and lobbies representing the views of groups of those particularly vulnerable to COVID19 (both the elderly and those with diseases placing them at particular risk) should be consulted. Most vulnerable persons are autonomous, competent and should be allowed to voice their own opinion.

Unresolved issues

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Appendices