

PHED

precision health and
everyday democracy

REPORT #1

PHED COMMISSION ON THE FUTURE OF HEALTHCARE POST COVID-19

SOCIETAL INEQUITY MAKES US
VULNERABLE TO PANDEMICS

BASED ON PUBLIC SESSIONS CONDUCTED
OCTOBER TO DECEMBER 2020



STINT

Stiftelsen för internationalisering av
högre utbildning och forskning

The Swedish Foundation for International
Cooperation in Research and Higher Education

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EXECUTIVE SUMMARY

During Fall/Autumn 2020, the PHED project between Malmö and Lund Universities organised a Commission inviting oral and written testimony on the future of healthcare post Covid-19. Focused initially on the Scania region, the discussions expanded to include a wider Swedish national focus, and international comparison with France and the United Kingdom. The inquiry included testimony from healthcare practitioners, civil servants, civil society, as well as researchers. Overall, the testimony pointed to Covid-19 as both a tragedy and a learning moment by which to strengthen society. It identifies several key recommendations for protecting and improving public health.

SIX CORE RECOMMENDATIONS:

1. COMMUNICATION FOR HEALTH

- a. Health communication must acknowledge that people live diverse lives, with information and guidance designed on that basis.
- b. Health communication must use multiple channels to reach a diverse population, accepting that it should not be exclusively online.

2. STRUCTURAL BASIS OF HEALTH INEQUITY

- c. Ensuring good population health requires identifying structural barriers that disproportionately harm marginalised groups.
- d. These barriers need to be understood as not only impacting marginalised groups, but undermining the entire population's health security.
- e. The above actions will only be possible if combined with concerted efforts to counter potential stigmatisation of marginalised groups.

3. LIVING CONDITIONS AND EMPLOYMENT IMPACT HEALTH

- f. Housing policy at all levels needs to be evaluated and designed with a focus on enhancing human health.
- g. Labour policy at all levels needs to be evaluated and designed with a focus on enhancing human health.
- h. Housing or labour conditions that undermine human health need to be understood as posing a security threat to the national population due to their knock-on societal and economic effects, as evidenced during Covid-19.

4. HEALTH IS AFFECTED BY RESIDENCY STATUS

- i. Health workers and other public officials (e.g. police) need to both receive clear guidance, and be able to communicate that information, on what healthcare is available to persons who lack residence permits.

- j. Healthcare access must not be dependent on having a secure internet connection, due to internet poverty disproportionately affecting migrant groups.
- k. Inadequate housing and employment conditions imposed on asylum seekers need to be understood as harming both those individuals' health and that of the wider population.

5. THE HEALTH ROLE OF CIVIL SOCIETY ORGANISATIONS

- l. Civil society organisations should be recognised for their work in maintaining society during Covid-19, particularly where the state has reduced its role.
- m. The role of civil society needs to be evaluated vis-à-vis that of the state, to identify where state funding should be either reallocated to civil society or to increasing the role of the state's service provision.
- n. The role of civil society should not distract attention from concerns over the apparent failure of the state to act in reducing the societal impact of Covid-19.

6. NETWORKING BETWEEN STATE AGENCIES

- o. Specialist agencies experienced in the needs of marginalised communities need to be financed so that they can contribute that knowledge within the network of state agencies.
- p. Centralised state control must not risk undermining the competence of those smaller state agencies more familiar in the needs of a diverse population.

1. COMMUNICATION FOR HEALTH

The communication of essential information on Covid-19 was one of the most commonly mentioned issues raised by those giving testimony as an ongoing problem throughout 2020. Based on that testimony, we identified two key recommendations:

- a. Health communication must acknowledge that people live diverse lives, with information and guidance designed on that basis.
- b. Health communication must use multiple channels to reach a diverse population, accepting that it should not be exclusively online.

Failure to recognise the needs of a diverse population when communicating health information during the first year of the pandemic was seen to disproportionately affect those parts of society living at its economic margins. In addition, whilst marginalised individuals often understood the need to, for example, socially distance, they felt ignored by centralised health messages that did not recognise the reality in which their precarious employment in frontline sectors (e.g. nursing, transportation) meant they were unable to realistically follow such guidance. Health communication was perceived as often tailored to only relatively affluent groups with little consideration for those with fewer options to socially distance or self-isolate.

In Sweden, as in many European countries, a disproportionate percentage of marginalised groups consists of newly arrived migrants. Mia Sandor from the Centre of Excellence in Migration and Health (CEMH) of Scania Regional Council, which has the highest percentage of newly arrived migrants in Sweden, explained how their organisation played an important role by trying to include a migrant perspective in healthcare, by mapping what information was accessible to migrants and how interpretation ought to be done facing restrictions on social distancing:

“ [...] obviously with covid-19 and trying to use as much physical distance as possible, we recommended that you use an interpreter over the phone, in some cases if you still need an interpreter [...] at the units you should still do so, but make the safe precautions to do so but otherwise you can do interpretation over the phone. So it's extremely important that we reinforce that because sometimes in times of crisis you kind of exclude those extra things but as we all know it's extremely important to be [...] able to understand and being able to communicate in a way that everyone understands.

Sandor further acknowledged the importance of both translation and interpretation, stating that “some information you want to have written [...] to read from home”. She also noted structural obstacles and the value of pre-established strategies to ensure quick translation:

“ if a single unit wants to translate something you have to pay for it yourself, but if it's something that we have a strategy for and if you need this information and this is covered centrally then the odds of that being conducted is much greater.

For Sandor, it was important to focus also on strengthening the health literacy of marginalised groups, by holding discussions in which one draws out the links between healthcare and broader lifestyle choices to help individuals build strategies to counter some of the negative effects of poverty on their wellbeing:

“ I think bringing up that topic is very important in the discussion as well. What are we supposed to do in healthcare? Are we supposed to just address the issue that you come for, or are we supposed to talk about health in general and how you can affect your health in the long run doing certain things?

Several seminar speakers talked of the importance of lifting specific group needs while avoiding blaming or stigmatising those most vulnerable. Regarding the Somali-Swedish group who were disproportionately affected by the pandemic early on, Anna Bredström of Linköping university, who has been conducting a research project on health communication during Covid-19, identified prejudice against Somali groups that distracted attention away from the responsibilities of the healthcare system:

“ they said they really felt that there was a lot of discussions and thoughts and ideas about that Somalis lack knowledge and couldn't take care of the communication or understand the communications because [...] they were having this kind of traditional cultural religious practice. So this discourse [...] is really something that we

recognize when we talk about migrant integration issues in Swedish society in general. And this was of course also prevalent in relation to Covid-19.

A common problem, especially for marginalised groups, was difficulty accessing information due to the choice of particular channels in which they were disproportionately excluded because they, for example, lacked technological access or knowledge of the healthcare system.

Mia Sandor at the Centre of Excellence in Migration and Health, Scania Regional Council noted the following:

“ you have a view of your patient as a person who has health literacy skills, knows where to look for information, so we have certain platforms where you provide information. But if you have no idea of where to look then this information won't reach you.

Accessibility was also addressed in terms of practical obstacles to finding information. Lina Al-Nahar, founder of the interprofessional working group for adjusted health information regarding Covid-19, told us:

“ People talk about mobile phones and computers and the Internet, and it may be so that [...] people have [a] mobile phone. But still maybe they don't have computers or they do not access the

Internet. So even when the, this information came in other languages from the [Public] Health Agency in Sweden, they only put it on their website.

Similarly, Louise Dalingwater, professor at Sorbonne university and who has been conducting research on migrant healthcare during Covid-19, told us that in the interviews she had conducted with civil society actors in the UK and France they had noted that

“ people in excluded groups are often unable to access online information, [a] lot of information is online in most European countries [...] so they couldn't pay for access for example for broadband...they may not have had the knowledge or digital skills to be able to access the information. The information was perhaps written in a language that's not understandable and maybe in a limited number of languages. It's not necessarily appropriate for excluded groups with low literacy levels. Guidance was not targeted enough at those socially excluded groups and support services and networks which would normally be there to help and transmit the information were closed.

Several of those providing testimony pointed to the need for information distribution targeted specifically to different groups as one way of better protecting marginalised groups.

2. STRUCTURAL BASIS OF HEALTH INEQUITY

All those who presented evidence to the Commission pointed to the existence of marked health inequity, in which groups already marginalised within society were then most likely to experience the impact of Covid-19. The testimonies point to the following key recommendations:

- c. Ensuring good population health requires identifying structural barriers that disproportionately harm marginalised groups.
- d. These barriers need to be understood as not only impacting minority groups, but undermining the entire population's health security.
- e. The above actions will only be possible if combined with concerted efforts to counter potential stigmatisation of marginalised groups.

According to Anna Bredström, senior lecturer and associate professor in Ethnic and Migration studies at Linköping university, the need to better understand health inequity is complicated by broader political attitudes where those often most affected by the pandemic are immigrants living in relative poverty within Sweden. She stated:

“ Immigrants from low- and middle-income countries are approximately twice as likely to die as compared to individuals born in Sweden [...] there are many studies that have shown this

health disparity. So [...] the key question then is how is this explained? [...] We want to understand how [...] ethnic differences in health and ethnic health disparities are approached and understood by the Swedish authorities and [...] look at how is this explained by different actors working with medical research policy and clinical practices.

Analyzing press conferences by the Swedish Public Health Agency in 2020, Bredström noted:

“acknowledging the socio-economic perspectives is really good and helpful but [...] these discourses tend to reduce ethnicity to class [...] instead of also taking into account the structural racism that exists in society [...]. Of course we need to acknowledge cultural differences; [...] we just need to not do it in a way that stigmatises people and to treat culture as something static.

In the UK, Frances Webber, human rights lawyer and vice chair of the Institute of Race Relations, had also noted how structural discrimination and racism were at times reduced to attitudes and policies, and that pre-established feelings of the “us” and “them” risks putting people’s health at jeopardy in a crisis such as the pandemic:

“since the pandemic really started it's been absolutely obvious and there have been dozens and dozens of studies which have shown the massive disproportion both in terms of infection and in terms of death rates among black and minority ethnic people. The first 10 doctors to die of Covid were ethnic minority. And [...] the Filipino Nurses Association UK said that more Filipino nurses had died in the UK than in the Philippines.

Thus, Webber and Bredström highlighted the acknowledgement of institutional racism as a way forward to ensure equality in health.

All eight seminar speakers acknowledged that groups that were marginalized prior to the pandemic had been disproportionately affected. Solvig Ekblad, licensed psychologist at the Academic Primary Health Care Center and professor of multicultural health and care research at the Karolinska Institute told us:

“So what do we know about the risk of being affected by Covid-19? We know that the morbidity and mortality for ethnic minorities and lower socioeconomic status both in Sweden, UK, major cities in [the] United States and also reports from [the] WHO European office in Copenhagen.

We know that it's an increased risk of stigma, [...] [and] discrimination in the wake of [the] pandemic. And also the risk of a low health literacy, mistrust to authorities, including health care and delay of health seeking.

Because of these disparities, Ekblad continued:

“We need to protect particularly vulnerable groups, newcomers, the elderly [...] those with underlying illnesses and bad nutrition [...] equal right to relevant health information for all citizens by dialogue. Counteract mythmaking and harmful strategies that are developed when government recommendations are perceived as not sufficient, unclear and irrelevant. And reduce the social spread of the infection within the area and to other areas with contact service professions and at last, limit the risk of increased stigmatisations of already exposed residential areas.

The difficulty of following the recommendations due to one’s living situation was mentioned by all seminar participants. Louise Dalingwater, professor of British Politics at Sorbonne university, noted the importance that “communities and government are aware of the situations and these vast inequalities in terms of health and social conditions”.

3. LIVING CONDITIONS AND EMPLOYMENT IMPACT HEALTH

The Commission heard from both those working directly with healthcare as well as the researchers that human health needs to be understood holistically, meaning that it is not only a matter of what the healthcare system provides, but has much to do with other factors impacting an individual's life quality. Amongst those factors, two important aspects evidenced during the first year of Covid-19 were living conditions and employment status. The latter concerned both whether an individual had stable employment, as well as their labour conditions. This leads to the following key recommendations:

- f. Housing policy at all levels needs to be evaluated and designed with a focus on enhancing human health.
- g. Labour policy at all levels needs to be evaluated and designed with a focus on enhancing human health.
- h. Housing or labour conditions that undermine human health need to be understood as posing a security threat to the national population due to their knock-on societal and economic effects, as evidenced during Covid-19.

Martin Grander, researcher at the department of Urban studies at Malmö university noted how:

“It became painfully apparent now with this pandemic how housing has such an important significant role in dealing with this crisis [...] the elders are said to isolate at home, young people, children and students are having their education from home. So the home is of course of utmost importance for this [...] pandemic. And as we're seeing how the home is becoming in the center of attention here we [are] also seeing how new everyday patterns are emerging and that of course relates to the general welfare society, how welfare services are directed to the home.

Lifting results from his 2020 report *Increased inequality in housing in the wake of the Covid pandemic*¹ he explained that there is a need for a number of reforms connected to housing if we aim to decrease inequality. These reforms were needed, he said, as “where we have the highest degrees of crowding, the highest degree of public housing and the highest degree of low-income households we also have [the] largest number of cases per inhabitants”. He explained that exposed households face a double vulnerability:

“by that we mean that they are on the one hand living in crowded households, in marginalized areas where they have less possibility to isolate in their homes, they are many families, members, and generally many people living in the apartments. We have seen that the crowdedness has increased also [...]. On the other hand [...] if they are employed they are often employed where they have no real opportunities or possibility to work from home, but they have to expose themselves [...] in the services and so on which means that they have to commute [...] they have to expose themselves to people and they become more vulnerable.

This double vulnerability was brought up in all four seminars. Anna Bredström at Linköping university noted how the same people who are living in poor conditions and crowded housing also

“have no alternative but to use public transport [...] and their vulnerability is also enhanced by the fact that the same group of people are also working in places where they are more exposed to the virus [...]. Many of them are for instance taxi or bus drivers or work in home care services and cleaners and so on.

Lina Al-Nahar, founder of ArtCovid, also mentioned that the restrictions were good “but very selective ones”:

“They were for the people who actually could work from home [...] it was not [...] for the nine persons in the two bedrooms. Neither it is for people living across generations, with elderly and schoolchildren [in] the same room. [...] we had this ‘keep distance to the sick and elderly’ and that was not possible either, if you are living crowded.

Nicolas Lunabba, head of the civil society youth organization Helamalmö, noticed how Covid-19 became an additional crisis for many young people who live a life in which crisis was the normal even prior to the pandemic:

¹ The report is available online: <https://www.delmos.se/wp-content/uploads/2020/11/Grander-och-Salonen.pdf>

“ [...] the day before we shut the whole [meeting place] down there was a murder in Malmö. So there was this young guy who was killed and a couple [...] of my colleagues knew him. So from reorganizing, from one crisis and one situation, we had to adapt to another sort of crisis.

To avoid counterproductive consequences, Lunabba saw that it was necessary to not exclude consideration of already existing crises and their effect on marginalised groups when working to manage the Covid-19 crisis.

4. HEALTH IS AFFECTED BY RESIDENCY STATUS

The role of marginalized migrants' vulnerability was a recurring theme throughout the seminar series. Even where those lacking residency status were given special exceptions to receive healthcare related to Covid-19, such as tests and treatment, health exclusions occurred due to: fear of the actual/perceived risk of deportation when seeking help; poverty related to their residency status that meant individuals lacked a reliable internet connection by which to access healthcare when face-to-face consultations were largely stopped during the pandemic; inadequate living conditions for those seeking asylum; and, little or no employment options for those seeking asylum. This leads to the following recommendations:

- i. Health workers and other public officials (e.g. police) need to both receive clear guidance, and be able to communicate that information, on what healthcare is available to persons who lack residence permits.
- j. Healthcare access must not be dependent on having a secure internet connection, due to internet poverty disproportionately affecting migrant groups.
- k. Inadequate housing and employment conditions imposed on asylum seekers need to be understood as harming both those individuals' health and that of the wider population.

While Anna Bredström noted that “racialized minorities and migrants” had been affected “much more by the pandemic”, Frances Webber of the Institute of Race Relations, the Centre of Excellence in Migration and Health and Louise Dalingwater at Sorbonne university all mentioned the role of legal status in access to healthcare services. In their overview of how Europe was dealing with the pandemic, the Centre of Excellence in Migration and Health found that there was: “around Europe insufficient access to health care. We know that there is, depending on what migrant status you have - if you're an asylum-seeker or if you're undocumented or quota refugee or what it may be, you have different access to healthcare in different European countries. And the same goes for Sweden obviously”.

One's legal status may also be connected to the type of housing one resides in, which was the case for asylum seekers in the UK and France. While Louise

Dalingwater lifted difficulties of following social distancing and hygiene regulations in makeshift camps outside of Paris and in the Calais region, Frances Webber at the IRR told us the following of an asylum housing contractor in the UK:

“ the local [...] public health authority accepted the argument of [...] the asylum housing contractor that this was one household. One household comprising 264 people for the purpose of locking down. Which then let the contractor off the hook in terms of covid security inside that building. It was horrendous, and needless to say there was an outbreak and eventually everybody had to be dispersed to other places, I don't actually know where they went. But I do know that they weren't tested before they went. I mean, there were some who were symptomatic who were quarantined but the others were not tested, they were just dispersed. At the height of the pandemic another large group of people, over 300 people were taken, asylum seekers, taken from their self-contained accommodation in Scotland [...] in vans obviously sitting very close together, to hotels in Glasgow where once again they were forced to share accommodation. Not only that, they had no, absolutely no money.

Webber stressed the insecurity of short-term visas linked to one's workplace where absence from work could result in both being let go and losing rights to reside in the UK, but also the legal status shaping health access:

“ most migrant workers [...] until they get a settlement visa, they have a condition on their visa which is no recourse to public funds [...] and the

home office has refused to lift that condition during the pandemic. So obviously vast numbers of people in the UK have lost their jobs, and [...] millions of people have applied for and got welfare benefits. But for migrant workers who have this condition of no recourse to public funds, what that means is that if they are made redundant or if they lose their jobs, they have literally no support at all. And so there are, it's been estimated [...] that there was 1.4 million people in the UK with that condition who cannot access any kind of benefits at all. So what you're seeing is vast numbers of migrants having to, those who have lost their jobs having to maybe sofa surf so staying with friends or whatever, in pretty grim conditions very often. And you also see a lot of migrant workers who cannot afford to stop work.

Both Webber and Dalingwater named health care fees as an obstacle for migrants to seek care. They also brought up, as did the Centre of Excellence in Migration and Health, that many migrants fear seeking healthcare in case their legal status is revealed or they are denied access due to lack of knowledge from healthcare staff or because of prejudice and racism. The Centre of Excellence in Migration and Health also saw new migrant groups not gaining access to healthcare during the pandemic, such as people on tourist visas having to overstay due to travel restrictions.

5. THE HEALTH ROLE OF CIVIL SOCIETY ORGANISATIONS

The importance of collaboration for better crisis preparedness was lifted by several of those providing testimony to the Commission. Civil society often not only supplemented the states' role, but often filled in the vacuum where the state has withdrawn health and other social services during the last few decades. Civil society organisations therefore proved essential in maintaining society during the height of the pandemic, but as very uneven and often poorly financed networks of organisations, the provision of support was less coherent than might be expected with state-based actions. This leads to the following recommendations:

- l. Civil society organisations should be recognised for their work in maintaining society during Covid-19, particularly where the state has reduced its role.
- m. The role of civil society needs to be evaluated vis-à-vis that of the state, to identify where state funding should be either reallocated to civil society or to increasing the role of the state's service provision.
- n. The role of civil society should not distract attention from concerns over the apparent failure of the state to act in reducing the societal impact of Covid-19.

As mentioned in section one, Bredström saw the need for conceptual clarity across scientific disciplines to better understand health disparities. Collaborations between at-risk communities, decision makers and researchers were upheld by both Ekblad and Al-Nahar. Several of those who gave evidence particularly addressed the important role of civil society during the pandemic. The Centre of Excellence in Migration and Health noted that for them, “sometimes NGOs [have] the most important perspective on what access [to healthcare] patients have”. Louise Dalingwater of Sorbonne university told us:

“ I think the question of making the public aware of the situation [for marginalized migrants] and the difficulties is an important role the civil society has been playing as well during this pandemic [...] in light of these health and social issues which is facing migrants, the civil society groups have become facilitators to ensure that migrants have access to health and social care. And these interventions take place on [the] premise that access to high quality healthcare is actually a basic human right. [...] In the wake of this crisis civil society have served as an advocate, as a watchdog, and a trusted authority.

In their work toward creating adjusted information material for different language groups, Lina Al-Nahar told us:

“ we made a focus group in Malmö and for that we had [the] Iraqi Association in Malmö who helped us. And for the focus group to actually, read through our advices [...] adjusting [...] not only learning the language, but also which levels and which way we can reach the people to give them this information.

The Centre of Excellence in Migration and Health's pre-existing collaborations with NGOs had proved helpful during the pandemic:

“ [...] two years ago we started this network together with them because we felt like we needed some input from the NGO sector [about] our patient group. We wanted to have some more information on [...] the access [and provision of] healthcare and do they feel that [...] there are some issues that we need to address. [...] and we meet like once or twice per year, so what we did when Covid hit us was that we got together like an extra time [...]. And at the same time we invited the Infection Control Unit of Scania so that they together could discuss the issues that they saw as NGOs meeting the population, the migration groups which is of course mainly asylum-seekers or undocumented [...]. And so the Infection Control Unit of Scania could [...] ask questions on what, how do we do, how do we get access to healthcare in this situation. Are these tests [are] also for free if you are undocumented and so on. Where can I look to get information if I don't read, for example. [...] And I think this was also the start of a collaboration between the Infection Control Unit of Scania and the NGOs in a more hands-on [way]. [For] example the infection control of Scania [...] visited Scania Regional Government just to see how they could provide a safe environment in their locations because [...] they met a lot of people [who] continue to come to their facilities of course because they still needed food, they still need treatment. So how can we together work out a way to make it a Corona safe environment. So that was one of the collaborations that came out of that meeting with the network. And that was very, a very positive experience, I think.

NGOs in France and the UK had experienced limitations and challenges in their work during the pandemic. Louise Dalingwater told us:

“ Doctors without borders who we interviewed in France and L'Auberge des Migrants in the Calais region said that there had been coordinated meetings with local authorities to see and to provide health and social care to migrants but on a regular basis, but they actually fell apart after the first lockdown. And Doctors Without Borders France told us that the region [...] which is basically responsible for leading health response in the regions were actually totally absent from these meetings. And the NGOs that we interviewed in the UK reported an absence of coordination too.

“[...] there are of course limitations in terms of what civil society can do and particularly NGOs in intervening. In terms of providing shelter there are obviously limits, shelters which respect social distancing. [...] there's a huge problem

in providing accommodation for marginalized migrants, newly-arrived refugees in France. And this cannot be done [...] on a large scale by these associations, it requires government intervention. The housing ministry and local accommodation action, investment, and preparedness which is not in place [...]. We also need coordinated and consistent policies between the state and civil society and this seems to be intermittent and sometimes completely absent.

Another way of alleviating the work of civil society, Louise Dalingwater continued, could be with multi-sectorial partnerships where researchers could play a role in providing an overview of role distribution. She said:

“ [...] one case in point would be the work that's been done by Aurore [...] the lady that I interviewed, she was a social worker, she was very much aware of what was going on [...] in her association and the difficulties that the marginalized migrants that she's dealing with [...] but she didn't necessarily have a wider picture to present so she [...] wasn't aware for example of any discrimination. And she wasn't aware of [...] who they could as an association reach out to. So I think obviously when they're working on the ground with the tremendous amount of work that they are doing it's actually quite difficult for them to have an overall perspective. [...] in the UK [...] they had a better overall picture but certainly in France it seemed that they were very much regionalized or localized in their work. So it's actually quite difficult to bring together all the work that was being done and also understand the limitations and how they could overcome those limitations. So possibly our work [as researchers] would be to actually bring together those different experiences so that we can see that there is common ground and there are limitations that really need to be overcome.

6. NETWORKING BETWEEN STATE AGENCIES

State agencies have performed best where they have been able to successfully coordinate with one another, via pre-existing networks that could adapt to the Covid-19 crises and strengthen the resilience of society and the state. This leads to several recommendations:

- o. Specialist agencies experienced in the needs of marginalised communities need to be financed so that they can contribute that knowledge within the network of state agencies.
- p. Centralised state control must not risk undermining the competence of those smaller state agencies more familiar in the needs of a diverse population.

The Centre of Excellence in Migration and Health had collaborated both within and outside their organization during the pandemic. They told us:

“ We also had collaboration with the county administrative board and their health communicators in producing different videos on different health issues and these were partly on covid-19 so, what is it, how is it transmitted... how and where do I seek [...] healthcare. This is something that we collaborated obviously with the Infection Control Unit in providing information to the County Administrative Board on the manuscript of those videos.

There were also challenges that made the Centre of Excellence in Migration and Health further point at the importance of pre-existing connections within and between state-funded agencies to ensure clear responsibilities:

“ [...] we didn't know, who is supposed to do this? [...] is the national information, should they provide the information that is on 1177 [...]? So it took us maybe three weeks before we had our own information and we knew, [...] at least for now [what] is needed. So everything [...] took some time to get through and I think that [...] the lack of bigger picture is one thing that made it harder. And of course, as I said, the value of existing collaboration that was again I think our main key to our success at least and how we could get the work done in [an] efficient way.

The collaboration with national organs, they continued, made possible a two-way communication with non-Swedish speakers. Information chains

were otherwise “like a one-way street” with little possibility to ensure that information was understood and with no chance of asking questions:

“ There's also a national phone line [...] that provides information about Covid-19 and answers questions about Covid-19 in different languages. And this is something that started in Stockholm [with] the health communicators there [...] a supplement to the advice that 1177 is giving. [...] So after Stockholm started this and there [were] discussions about this being a national phone line, this is now with the aid of the Swedish Public Health Agency [...] a national phone line.

Regarding collaborations and needs moving forward, Louise Dalingwater said:

“ [...] there are a number of recommendations that could be made, but the obvious one is the need for more coordinated multisectoral partnership, across the board. A policy approach needs to take in to consideration that high quality healthcare should be provided with social care for all patients as a basic human right. And it's only when there's a true consultation for needs and the capacity required with government to provide such conditions that we can, we will be able to fully achieve this.

CONCLUSIONS

Whilst the Commission was held publicly, and all oral testimonies received have been archived online, it was not a public consultation to the extent that we heard from only a relatively small group of healthcare practitioners, civil society, and researchers. Covid-19 restrictions meant we were only able to hold the sessions online, potentially limiting some forms of interaction, and we would have liked to receive many more submissions than those on which this first report is based.

However, it is also important to state the value of archiving the experience of those who have either direct or comprehensive knowledge of the societal impact of the pandemic. The persons who gave testimony are dedicated and highly skilled in the field of health and healthcare, many of them focused on the margins of society where we see the limits of present health and social policies.

That there is a significant emphasis on the disproportionate impact of the pandemic on individuals with precarious residency status, due to being newly arrived migrants, is a reflection of the extent to which these individuals today make up a significant percentage of those living on the margins of Swedish, French, and UK society. The politics around migration should not distract us from seeing what can be learnt about the weaknesses, and strengths, of our current social models as viewed from how they impact those living on society's margins. Covid-19 shows us that society's strength is dependent upon how it ensures equitable treatment for its marginalised groups, since their health problems undermine the health of the entire population. Any suggestion that marginalised groups are themselves the problem prevents us from learning how to maintain and improve our societies.

Already there is a wealth of evidence being published stating the societal impact of Covid-19, much of it highly well-researched and supported by extensive data. There is, also, a need for more interdisciplinary research capable of addressing the complex role health and healthcare play in society. Health is an issue that speaks directly to the individual, sparking both interest but also provocation where stark inequity leaves some feeling disenfranchised, whilst also demanding major societal reforms with economic consequences. The report presented here is intended to offer a light, however small, by which to find our way through this maze. It is important to search for evidence, to identify the costs and consequences of our present-day policies, so to be able to decide rationally where reform is needed to help our societies survive. The testimonies and recommendations provided are based mainly on

the Swedish experience, but from international testimony and what we see elsewhere, we know that they remain as relevant, if not more, to many of the most affluent states in the world today that have the most to lose if they fail to heed the warnings learnt from the Covid-19 crisis.

The PHED project. Malmö and Lund, April 2021.

BACKGROUND ON THE PRECISION HEALTH & EVERYDAY DEMOCRACY (PHED) PROJECT

Since 1st January 2019, Lund and Malmö Universities in Sweden have collaborated within an international project that now includes partners from at least 9 countries and across 3 continents, brought together around the interdisciplinary theme of 'Precision Health and Everyday Democracy'. The project is funded thanks to a competitively won grant from the *Swedish Foundation for International Cooperation in Research and Higher Education (STINT – Stiftelsen för Internationalisering av högre utbildning och forskning)*.

Recent advances within healthcare and medical research have been uneven globally, but also within nation-states, with the result that there is growing interest in the relevance of both environmental and genomic factors in determining how best to treat patients and ensure a healthy society. At the same time, health has become an increasingly central issue within how societies mark out their borders and internal structures, excluding those without the sufficient residency papers, or segregating access along wealth, racial, or gender lines. In that context, health practitioners have spoken increasingly of 'Precision Health', meaning greater understanding and collection of data that is sensitive to these disparities so as to better tailor healthcare towards different communities, both to enhance well-being, but counter the worst consequences of societal inequalities.

Drawing on the Social Sciences, health is understood as a central mechanism not only for enhancing welfare but also through which everyday people experience being part of society. For over two decades, scholars working in both the Health and Social Sciences have spoken of 'Health Democracy' – using democratic models to enhance patient access to healthcare, but also to better study the role of healthcare and medical research within society. We use the term 'everyday democracy' to move further in that direction, understanding medical and health interactions as fundamental to the shaping of contemporary society.

Healthcare is not only what occurs when we visit the doctor, or receive medical treatment in a hospital. Before we get to that point, we need access to healthcare. It requires that we have the legal right and actual means to receive healthcare. It requires that we understand when to ask for help, what healthcare is available, and how to get it. And, more often than not, we realise that our healthcare requires certain living conditions (e.g. reduced working hours, exercise, etc) that can support both the prevention of, and recovery from, illness.

Health, healthcare, and medical research have a significant impact on what it is like to live in a particular society, including the extent to which we feel that society is functioning and able to provide a good quality of life. Not only is health and healthcare about our bodies, it also defines what it is to be human in our modern world. To understand the present, and improve the future, of human health and healthcare requires that we adopt a holistic view that cuts across disciplines as PHED proposes.

THE PHED COMMISSION ON THE FUTURE OF HEALTHCARE POST COVID-19 AUTUMN 2020 - PURPOSE AND TERMS OF INQUIRY

With a project focused on the societal role of health and healthcare, as the world woke up to the harsh reality of the global pandemic in early 2020, it seemed both logical and necessary that the PHED project adjust its goals to connect more directly to the immediate dilemmas facing society. Faced with a confused political and media landscape, we saw a need to give voice to those with immediate experience of what was happening. The voices presented here are only a fraction of those that need to be heard within the series of larger-scale inquiries to come, but nonetheless represent a series of valuable perspectives as we seek to better protect our societies from future pandemics and health-related crises.

The subsequent inquiry was titled the ‘Commission on the Future of Healthcare Post Covid-19’ for the reason that those experiences of a desperate present, as people working in the field struggled to find solutions that might keep the most vulnerable from dying, must not be forgotten as we look ahead to a life after the pandemic. As researchers running the project, our interest is in providing those oral testimonies so professionals working in healthcare, policy, advocacy, and other fields impacting human health may not only learn from these experiences, but also receive validation for their own efforts in seeking to improve the quality of human life for all.

Those who submitted oral testimony to the Commission came from different disciplines and lines of work: civil society, healthcare, policy, and research. Together, these oral submissions add perspectives of how collaborations, democracy, housing, migration and structural biases all play a role in the pandemic. We have sought to break disciplinary boundaries so that ideas can be heard across fields, avoiding traditional academic silos that can otherwise obstruct learning. Videos of the complete sessions were also recorded and archived online, within an expanding library of materials at: <https://phed.uni.mau.se/>.

We warmly thank all those who provided testimony for taking the time to recount their experience and expertise. In particular, we would like to thank Hilda Gustafsson, a PhD candidate employed to assist the Commission during Autumn 2020. Hilda chaired the sessions, who as a young scholar not only brought considerable energy and skill to the process, but also linked the Commission to the future development of research.

During Autumn 2020, the Commission focused primarily on soliciting submissions from Sweden, with the majority from the Scania region, and two testimonies from other countries – France, and

the United Kingdom. Both universities leading the PHED project – Malmö and Lund – are located in Scania. The regional and national focus was important for this first stage of the Commission process, strengthening the Commission’s capacity to engage with healthcare practitioners and other experts. Also, Sweden’s record as a leading welfare state with an advanced healthcare system serving a highly diverse population with a large share of migrants makes it a particularly interesting case study regarding the healthcare system during Covid-19. The French and UK comparisons provide an international context, drawing out key similarities with the experiences evidenced in Sweden. All oral submissions were given in English for the purposes of sharing the recorded experience with an international audience.

THE REPORT CONTAINS ORAL SUBMISSIONS ON THE FOLLOWING TOPICS AND INVITED TESTIMONIES

- *Conceptual unclarity during Covid-19.* Anna Bredström, senior lecturer and associate professor of ethnicity and migration, Linköping University
- *Experiences from civil society.* Nicolas Lunabba, head of youth organization Helamalmö
- *Grass roots organizations and marginalized migrants in the UK and France.* Louise Dalingwater, Professor of British Politics, Sorbonne University
- *Protective measures against Covid-19 – A qualitative study of barriers and own strategies in vulnerable areas.* Solvig Ekblad, licensed psychologist at the Academic Primary Health Care Center and professor of multicultural health and care research, Karolinska Institutet
- *The importance of a systemic perspective on health information.* Lina Al-Nahar, founder and project leader of ArtCovid; an interprofessional working group for adjusted health information regarding COVID-19
- *Experiences and lessons learned so far regarding activities and strategies for Covid-19.* Mia Sandor & Micaela Nilsson, Centre of Excellence in Migration and Health of Scania Regional Council
- *How institutional racism damages migrants' health.* Frances Webber, human rights lawyer and vice chair of the Institute of Race Relations, UK
- *How inequalities in housing affect the pandemic, and how the pandemic, and how the pandemic aggravates housing inequality.* Martin Grander, researcher at Dept of Urban studies, Malmö University

THIS REPORT IS PUBLISHED

on behalf of the Precision Health & Everyday Democracy Project, April 2021. It has been authored by Hilda Gustafsson and Michael Strange, with additional contributions from Elisabeth Mangrio, Slobodan Zdravkovic, and Carol Nilsson on behalf of the PHED project. Any views or opinions expressed are those of either the person quoted, or the reports' authors, and do not necessarily reflect those of the universities or funding organisation connected to the PHED project.

The report is available online: <https://phed.uni.mau.se/>



ISBN 978-91-7877-137-0 (print)
ISBN 978-91-7877-138-7 (pdf)
DOI 10.24834

mau.se

The report is also available in Swedish.
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