

## **The early German response to SARS-CoV-2: Perspectives from a guinea-pig patient**

With daily scientific and media updates on SARS-CoV-2 the public interest in the world's biggest global health issue at present, the so-called novel corona-virus continues unabated. I became known as the first case in my home city in early March, a fame I could have done without. SARS-CoV-2 seems more deadly than the seasonal influenza viruses from what we know at present, yet being a middle-aged woman with no prior health conditions, I regarded the risk to fall seriously ill when contracting this virus as negligible. Statistics show that over 80% of cases only develop mild flu symptoms, so SARS-CoV-2 did not frighten me. I imagined that if one contracted it, there would probably be little difference to a common cold or flu, yet my experience of testing positive to SARS-CoV-2 taught me a different lesson.

My journey leading to a 'confirmed case' started in February. We had a long weekend at Lake Constance, spending much of it outdoors visiting various quaint towns and watching the carnival procession with its many witches parading through the streets and small lanes of Constance. On the way home I felt a sore throat and a dry cough coming on - nothing serious, just a little niggle and I blamed myself for not putting the scarf on properly on the last day when the weather had turned sour on us. A couple of days later I had to attend a meeting of European institutes in Spain. A colleague from another institute told me the day before the meeting that he would cancel the trip, as he didn't want to contract SARS-CoV-2. I almost laughed at him as this seemed overcautious to me. The city in Spain where the meeting was being held had by then only 1 registered infected person. Travelling and meeting people from various European countries would, of course, involve some low level risk but the chances to contract the virus seemed more than slight to me, so I went. The meeting went well and on my return, I was confronted with a different problem on the domestic front: my father had been taken to the emergency unit so I went straight to the hospital to see my father and spent a good part of the night there until eventually, at 2 am in the morning, he was taken to a ward. The next days were divided between working from home and going to the hospital. The initial low-level cold gained the added dimension of a rhinitis by the weekend. It was February after all, and I kept enough distance to my father who I didn't want to catch a cold on top of his ailments. But by Sunday afternoon I was exhausted and needed to lie down but I didn't have a temperature. On Monday morning I received the message that one of the participants in the meeting in Spain had been tested positive for SARS-CoV-2 on his return to Italy at the weekend, and we should all take the necessary precautions. Having a slight cold, I thought it was best to go and test. But then I almost froze as I realized that I had gone straight to the hospital on my way back from Spain and the implications this may have. I rang the hospital and told them what I had learnt and that there was a risk that I may test positive. The hospital staff said they would test my father and his room-mate.

### **The challenge of testing for SARS-CoV-2 and receiving the results**

Then it was my turn to get tested – no small task: The local GP informed me that he did not perform the test and referred me to the local health office. As soon as I dialed that number, a recorded message told me to ring back later. I repeated this exercise several times before I decided that the health office was a total no-goer. My next best bet was the emergency section of my local hospital assuming they would do the test. At least here I got through, but alas, was told they don't do it either. I should contact another hospital. That hospital informed me that their corona-virus consultation would start in half an hour and I should ring again then. I thought rather than waiting, I will just go - my husband kindly taking me there. I found the place as described, a door next to the main entrance - outside a box with paper masks and disinfectant. Nobody was outside, so I disinfected my hands, grabbed a mask and went in. The little room was already full with people filling in forms, sitting there coughing behind their masks. Eventually somebody gave me a form to fill in. This place had been set up at the weekend. One staff was telling another to keep all the doors closed. So here we were, all suspected cases, in a tiny non-aired room, some of us coughing into our masks, waiting, waiting – and one suspect wondered aloud, how a testing

station could have been set up like this with a good chance of contracting the virus while waiting: no fresh air, all suspects in a crowded small room and flimsy operation masks as the only protective gear. Some were sent home again – their cases did not warrant to conduct a test. It reminded me of HIV where testing has become more and more targeted even to the ludicrous extent I witnessed in Cambodia a few years ago where sex workers were grouped into low and high risk sub-groups depending on the number of sexual contacts and only the high risk ones were tested. I have always held the view that those who self-report to have been in a risk situation and wish to do a test, should be administered a test. Yes, it costs presently over 100 Euro to conduct a PCR test for SARS-CoV-2, it needs laboratory staff and the argument goes that one does not want to chock up the system with (unnecessary) negative tests. But the pre-occupation with high yield and restrictive testing guidelines may lead to overlooking many cases. At present it seems that even those who have no symptoms can infect others, as seems to have been the case with me as the person from Italy had no symptoms at that meeting. We had spent some 10-15 minutes together over lunch discussing research issues. The restrictions on who to test and the belief that we can follow up all the cases through tracing seemed to me out of touch with the epidemic even when I was tested. The people waiting with me did not seem hypochondriacs. They had been to regions where a lot of cases had been detected – one being Alto Adige – which a few days later was declared a red zone. On that Monday morning it was not a red zone yet, so testing restrictions applied. And I wondered: is it sensible to send away people who think they have been exposed? I personally feel that doing a few more tests rather than not enough would be a more adequate public health response as it is likely that many infected people are not tested at present.

After more than an hour I was called in to do the test and to give details of why I suspected to have been infected with the virus. Since I had been in contact with a confirmed case and since I had some of the symptoms, the medical doctor tested and registered me as a 'contact person' with the health office. He informed me that it would take about 5 hours to have the test results, and the health office would probably either contact me later today or tomorrow, and I should stay at home in quarantine. He gave me a letter with further details. The return trip home did not seem anyone's concern. I thought I'd better ring my husband as public transport could potentially infect more people yet thought it odd that nothing was said about how to get home. Then the waiting began.

The letter said that I should be contacted by the local health office. But the next sentence read: It may take the regional health office 2-3 days to contact you. Immediately I was confused: which health office did they mean – the local or the regional one? According to the national guidelines I should have also been contacted daily by the local health office to see how I am, yet nobody rang me. I was in quarantine – end of story, it seemed. Procedures by and large did not appear in place yet despite the national health minister telling us every week how well prepared Germany was. After a day, I thought, it's about time to find out the results. So I rang the local health office but did not get through. I tried the regional one and was told that I should ring the clinic. The clinic? But the letter says the health office should inform me. The number for the corona clinic either rang out or was engaged. I tried the local health office again. After many attempts I finally succeeded in getting an official on the phone who seemed surprised about my request. I wondered: am I the first one who would actually like to know a test result? She informed me that she is not allowed to inform me; I should contact the clinic. After I explained that I can't get hold of the clinic, and the letter clearly stipulates that information is provided through the health office, she promised to enquire internally and ring back. She confirmed with her boss that she would be allowed to inform me, but alas, she has no results yet. My surprised question of no test-result having come in the next day when I was told the test results would take about 5 hours was met with the concession that it's a matter of organization. They had so many people test yesterday; I would unfortunately just have to wait. Time is of the essence in an epidemic. If one tests positive, so many others become potential contact persons, so one wonders, why it should take 2 full days instead of 5-6 hours to receive a test-result? My only small success that day was to at least identify a direct

contact number I could call at the local health office. However, that day I really felt like the flu had hit me – shivers, drained of energy, yet still no temperature - so in between the various calls I crawled into bed and slept.

The next morning I rang my newly acquired number at the health office to be told that they are in a meeting. Someone will ring me later. Eventually around lunchtime the call came through that I am positive. Officials from the health office discussed the details with me in a long and thorough telephone conversation and asked me to name all the people that I met and spent at least 15 minutes with from Saturday evening, when I would have become infectious. I informed them that I had had slight symptoms such as a sore throat and a dry cough already before the meeting in Spain but they thought that this may have been an ordinary cold which may have made me susceptible to becoming infected. It is very likely that it happened that way, yet without comparing virus genotypes, tracing becomes an educated guess. I provided the health office with all the 'contacts' I had met since Saturday night including my father who had been in hospital for a few days. Thankfully he had tested negative as I was told on the same day. As far as my health status went, I informed them that I thought they could keep the hospital bed for someone more seriously ill, that in my view we could continue the domestic quarantine arrangement as I only had mild symptoms, but the health office decided that as a precautionary measure and since I was the first case in this city, they would put me in an isolation room at the hospital. Since nobody would be able to visit me, I should pack a bag for 2 weeks. As my husband and son had slight cold symptoms, they would be taken in a separate car to be tested and taken back home again and would then have to be in quarantine.

## Hospitalization

How do you feel when two ambulances arrive outside your house on the street and you are escorted by health staff in moon-suits? You wonder what the neighbours might think the problem is with this family. The question is: Is the moon-suit really necessary? Would simple protective gear in addition to a mask



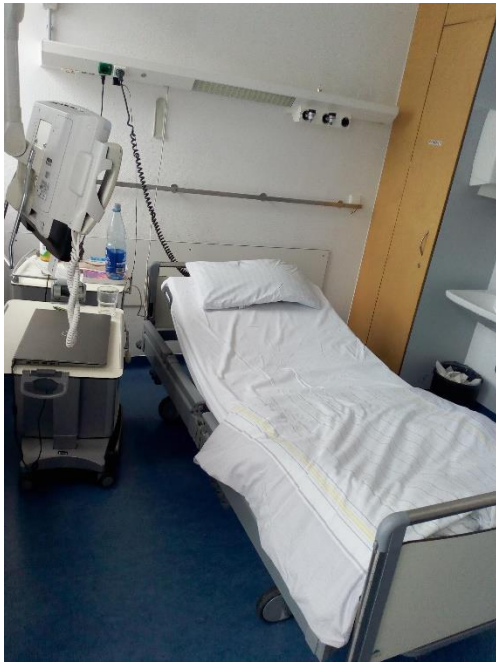
and gloves not be sufficient given that all of us also wore a mask and gloves? We are not dealing with Ebola, we are dealing with a virus which spreads via droplets. Seeing the Red Cross people arrive reminded me of a story a friend had told me about the very same hospital I was taken to where the Red Cross had to pick-up an HIV-positive man and walked into the ward with their moon-suits. The fellow patient in the room was alarmed as to what his neighbour may have, since the ambulance men arrived with all that protective gear. I think one seriously needs to look at the health sector's contribution to stigma through unnecessary and exaggerated precautions.

The doctors welcoming me at the hospital were taking the normal precautionary measures so I felt slightly more human again as I was being taken into my new abode – an isolation room, which, I was told, not to leave under any circumstances. The doctor, an infectious disease specialist, also worked in the field of HIV, so we already had enough common ground to talk about but I did not see him again until day 6 of my stay there. I could tell, he also thought it was not absolutely necessary to hospitalize me but they wanted to be sure they would do the right thing. He suggested leaving out any un-necessary examinations such as an ECG. In the end, I had blood drawn on the first day and blood pressure, pulse, blood oxygen levels and temperature taken, the latter sometimes several times daily.

While I generally only felt that I needed to get rid of my cold, what had already worried me at home was my pulse which seemed to be racing and was at 95 when I arrived. My blood pressure was also high:

160/100. It went back to normal the next day but from day 3 was up again to 170/95 and then seemed to switch between high and normal. Blood oxygen levels were okay, so my lungs did not seem to be affected.

By Friday night I knew that all the contact persons I named had tested negative – a big relief, yet I still felt ‘guilty’ for thwarting my son’s and my brother’s plans to embark on their respective holidays. They had to stay in quarantine despite their negative test results which were taken 4-5 days after possible exposure, raising the question: was it really necessary to put them back into quarantine after their negative test results? Could they still be in the incubation period with a negative PCR result? I think we need more clarity on these questions as the pandemic develops.



What were my own expectations of being in isolation? I firstly thought that with little distraction I would get a lot of my research work done, coding and analysing data, but I found, it was not so easy. Being in this hospital room with many friends, relatives and colleagues ringing and wanting to find out where one is and what happened and going through the daily hospital routines, I found myself googling a lot about SARS-CoV-2 and talking on the phone rather than focusing on the work I had wanted to get done. I also found that with no free internet in the room, I mainly used my laptop offline and therefore had to use the cell-phone concurrently which was more distracting.

Family and friends had been worried about the impact of not having any visitors. For me, this was not the toughest part of being in isolation. Being able to ring and to be rung meant I still felt connected even when I could not be physically present. Without a phone, hospital isolation would

undoubtedly be a much more traumatic experience. The worst part for me in addition to feeling like a bird in a cage was the sleep deprivation. Many nights I was woken up at 2:30, sometimes around 4 to be asked how I am! That was the end of the night for me. After a few nights of this I told off the morning nurse and asked not to be disturbed between 11pm and 6am – that I wanted to sleep! They respected this for one night - then unfortunately I was moved to the new isolation unit where I was not just woken up in the night to be asked how I am but where the nurse felt she needed to measure temperature and blood oxygen levels which had already be done at 7pm the previous night. Slavishly sticking to hospital procedures without any consideration for the health benefits of patients seems to me a counter-productive health measure which is hardly going to help corona patients to restore their health.

Almost all health personnel who came into my room in their protective gear were very friendly. They constituted my only direct social interactions. One nurse in my first isolation room at the hospital particularly went out of her way to make me feel comfortable: buying a sleeping mask when I asked if there was any way to darken the room at night; getting me a TV card so that I could watch the news. She always enquired what else I would need or want offering inhalation to get rid of the cough, bringing me fresh fruit and yoghurt or a salad as a healthier substitute to the high carb and fat evening meal. This nurse was not afraid to interact with me, and I highly appreciated the chats and all her help and assistance as I was not allowed leave the room and organize anything for myself. Some staff, I sensed, were scared to enter my room. Some would knock and shout that the tray is outside the door rather than bring it in. At times dirty dishes from three trays piled up inside the room as I had to wait until someone had the grace to come in and remove them. Standard hospital services like having the bed made or having the room cleaned did not happen daily. Tables were rarely disinfected, the rubbish piled

up a bit before it was emptied. It was nothing that really bothered me and I disinfected the surfaces myself, but it heightened the feeling of 'being left out', staying in a room that was probably catered for last, which some staff clearly wanted to leave as quickly as possible. My 10 days of hospital isolation gave me an inkling of how those suffering from highly contagious diseases must feel.

The set-up of the room with a small table and chairs and a hospital bed allowed some room in between which I used to do some exercises a few times a day to ensure my muscles did not shrink to nothingness. My second room in the 'proper' isolation station had even more space. Between cell-phone, laptop, books and exercises, the standard medical procedures, the meals and watching the news, the days passed but every new day increased a certain sense of boredom with the set-up, more sleep deprivation and the wish to return home. The infectious disease specialist had initially hoped that I might be able to return home a few days later, yet I needed to have 2 negative test results 24 hours apart. Among the 5 tests that were conducted, one was a false negative as the test had not been done with enough force.

### **Hospital release – back into quarantine**

Despite a positive result, I was released after 10 days of hospitalization back into domestic quarantine. It was unclear what this would mean for the rest of my family. I was told the health office would contact me to discuss the next steps. After innumerable times of trying to reach the health office, an official informed me 5 days after my hospital release that the German guidelines had changed: they would not perform another PCR test. Since I still had a cough, I should continue domestic quarantine. The new guidelines stipulate that patients can be released after 14 days of quarantine, if they have been asymptomatic for 48 hours. Yet, there have been cases where people have been asymptomatic, in quarantine for more than 2 weeks and were still testing positive. Since most health offices are stretched to the limit in terms of monitoring people in quarantine and since home visits do not seem to be carried out at all, an unclear end to quarantine without any test leaves it open to people how they want to interpret 'asymptomatic'. For many, it may just mean not having a temperature anymore. We need to know more about the duration of patients' infectiousness – most of all for the other family members living in the same household and for visiting older family members. Perhaps viral load tests would tell us more than PCR-tests, but using no tests at all to end quarantine seems to me a questionable decision.

Is COVID-19 worse than having a conventional flu? That depends on the person. In my case, the virus was neither worrying nor life-threatening as I only experienced a mild course of infection, but all the ado that surrounds COVID-19, the hype and fear in the population, the tracing, the quarantine, the isolation speak a different language. We have a strong obligation to protect those for whom this viral infection will be life-threatening, and we need to keep hospital beds for them. My own hospitalization seemed unnecessary, and transportation to and from the hospital by an ambulance with health personnel in moon-suits was a sure way to increase fear and stigmatization in the neighbourhood. It was early days in terms of the local epidemic, yet with increasing infections, we need to use hospital beds more wisely.

### **More not less testing needed**

The current testing restrictions in Germany seem to run counter to a public health approach. In order to protect the most vulnerable, we need to know who is positive rather than guess it. We should test at least those who have flu or cold symptoms or who have likely been exposed. To test more people, we will need faster and cheaper tests such as the rapid 15-minute test being developed in Taiwan which will hopefully get validated soon. It seems to me that Taiwan is one of the few countries that have controlled the novel corona virus. It is not prominent in the news, yet Taiwan has shown a remarkable concerted disaster-preparedness effort across all public institutions to detect cases and to follow up people who have been infected or are regarded at risk. It has also from the onset communicated openly to the population, and it seems this has avoided the panic mode that has seized many countries and achieved a buy-in from the population. Taiwan has controlled all border entries, collected information

about people's travel histories and health status testing and re-testing people, quarantining people and monitoring them. It may be worthwhile to learn from a country that seems to have got SARS-CoV-2 under control and to see which measures could be adapted. In order to have an effective response, we need to know who is positive but also who has recovered— a group which Germany has decided not to test anymore.

As we gain more insights from the epidemic in different countries, further adaptations may be necessary, yet local procedures need to be in place and communicated as to who can test, who should be in quarantine and who should be hospitalized. We need to expand testing to know who is positive and who has become non-infectious and can be released from quarantine or hospital. Testing, getting the results in good time and the measures taken thereafter should work efficiently and effectively, so that we can progress from this slightly chaotic guinea pig phase into an informed and effective response.