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Doctors in Chandigarh compelled to register for the voluntary National Health ID

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A view of the Government Medical College and Hospital in Chandigarh on 17 August 2017. AJAY VERMA/REUTERS

In early September, a junior resident doctor at the Government Medical College and Hospital in Chandigarh's Sector 32, spent three days trying to register with Digi Doctor—a registry of doctors that is part of the newly announced National Digital Health Mission 2020. The mission's stated aim is to provide a backbone to support an integrated digital health infrastructure for the country. "By the end of it, I was so frustrated that I called up the helpline number listed on the NDHM website and asked if it was mandatory for me to register," he said. "I was told that registering will be useful if I am a practicing clinician but is not mandatory. Then why was I forced to register when I am still a student?" At least five health workers from Chandigarh told me that they were compelled to enrol themselves in the doctor's registry, and to register for national health IDs under the mission even though it is supposed to be voluntary. All five spoke to me on the condition of anonymity.

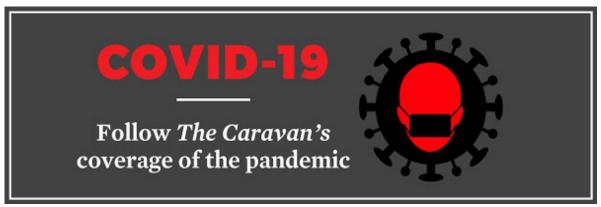
On 28 August, Jagat Ram, the director of the Post Graduate Institute of Medical Education and Research in the union territory, issued a <u>circular</u> (https://twitter.com/AnantBhan/status/1301174158882213890/photo/1), which stated that "registration for generating Health IDs is mandatory for all citizens of the country." Chandigarh is one of seven union territories that the National Health Authority—the autonomous body attached to the union ministry of health and family welfare that is implementing the NDHM—had selected for a pilot project under the mission. The PGIMER order further said that the Chandigarh administration had directed the institute to get all its doctors and their family members to register for health IDs. Other government hospitals and medical education institutions in Chandigarh, like GMCH 32, also issued such directions. However, Indu Bhushan, the CEO of the NHA had repeatedly <u>said</u>

(https://twitter.com/ibhushan/status/1295998180035686406) since the NDHM was announced that it was "a purely voluntary scheme with the citizens' rights at its core."

The NHA distanced itself from PGIMER's circular of 28 August in an emailed response to me on 4 September. Dr Praveen Gedam, the additional CEO of the NHA, who is in charge of implementing the NDHM, wrote that for the pilot project, "the generation of Health ID is purely a voluntary exercise i.e. it is a consent-based arrangement." Gedam added that authorities had been advised "not to issue any such orders and withdraw/amend any such orders if already issued."

In fact, the PGIMER backtracked and said that the term "mandatory" was an error that had been corrected. The institute issued a circular on 4 September stating that registering for health IDs was a completely voluntary exercise. "It is not mandatory per se, but it is just a good effort which will be successful if more and more people register, so we have only encouraged our staff to do so," Ram said to me. In his email, Gedam also referred to this circular and said that it "now has been clarified that the registration for generating health IDs is purely a voluntary exercise."

However, before PGIMER issued its clarifying order of 4 September, at least 57,000 health IDs had been registered in Chandigarh, according to data provided by Gajinder Dewan, the director of health services in Chandigarh. Dewan is responsible for implementing the NDHM in the union territory. According to the Gedam, 92,000 health IDs had been created across seven union territories as of 4 September. Even though PGIMER clarified that registering in the NDHM databases was voluntary, several doctors said there was a clear expectation of them to register. Some even accused the management of threatening them with consequences.



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Prime Minister Narendra Modi announced the mission on 15 August, in his address to the country on its 74th Independence Day and claimed that it would completely revolutionise the healthcare sector in India. The NHA issued a press release

(https://ndhm.gov.in/media/pressReleasePdf) on the same day, which claimed that the mission would "leverage power of technology to ensure the attainment of the highest possible level of health and well-being for all citizens." According to the NHA, the NDHM aims to create a "digital health ecosystem" in which digital health-information will be maintained under six different heads—patients' unique health IDs, the doctors' registry called Digi Doctor, a health-facility registry, personal health records, e-pharmacies and telemedicine.

The NHA started a pilot project in early August under the NDHM in seven union territories—Chandigarh, Daman and Diu, Puducherry, Dadra and Nagar Haveli, Andaman and Nicobar Islands, Lakshadweep and Ladakh. In a press release, the union health minister, Dr Harsh Vardhan, said that the learning from the pilot would be incorporated before the NDHM was launched in all states. The union ministry of health and family welfare had asked two institutes to start the pilot as early as the end of June. In an email on 30 June, a month and a half before Modi announced the mission, the ministry told the directors of the PGIMER in Chandigarh and the Jawaharlal Institute of Postgraduate Education and Research in Puducherry, to start implementing the NDHM by creating doctors' registries, health-infrastructure registries, health IDs and personal health records. Ram, the director of PGIMER, nominated a nodal officer to implement NDHM at the institute.

Though PGIMER officially said that its employees are at liberty to not register for health IDs, the situation on the ground is starkly different. A senior-resident doctor from PGIMER's department of general surgery told me that the hospital initially gave its staff a deadline of 48 hours to register for health IDs on the NDHM website, and to initiate their validation processes for registering as Digi Doctors. "In early September, the 48-hour deadline was removed, but it is still mandatory for all doctors to register themselves for health IDs as well as Digi Doctors," the senior resident said. "Even if they don't say it on paper, it is an unsaid expectation that all have to be registered eventually."

A doctor from PGIMER's transfusion medicine department told me about repeated messages that the department's administration would send on a WhatsApp group for department staff. These messages would ask whether the staff had registered themselves and their families for health IDs. On 4 September—the same day that PGIMER issued its clarifying circular to say that registration was voluntary—the department administration sent a message that threatened its doctors with consequences if they failed to register. The message said that it "was brought to the attention of H.O.D that you have not submitted Health ID till date." The transfusion-medicine doctor said, "We also received a message today saying that if we don't register soon, a non-compliance report will be sent to the director."

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"This is a common modus operandi, which we have also seen with Aadhaar and Aarogya Setu, where you make sure everything is voluntary on paper but then you issue different instructions to officials on the ground," Devdutta Mukhopadhyay, an associate counsel for the Internet Freedom Foundation, said. The IFF is a digital-liberties organisation that has closely monitored the pilot project, as well as, the progress of the draft Health Data Management Policy. The draft Health Data Protection Policy (https://ndhm.gov.in/health_management_policy), which sets out the foundation of the NDHM and is currently under public consultation, also lays out a detailed system of consent management where the individual whose data is collected and linked to his or her health ID is supposed to have the right to opt in or out of the "NDHM ecosystem" at any time. Mukhopadhyay, along with other members of the IFF, and Dr Satendra Singh, a disability-rights activist, filed a petition in the High Court of Delhi on 2 September, which challenged the initial consultation period of a week given to stakeholders to provide feedback on the draft of the policy.

The PGIMER is far from the only medical institute in Chandigarh to issue instructions to government healthcare staff that fly in the face of the NHA's assurances of voluntary registration. The GMCH 32 had issued a circular on 18 August signed by the joint director of the hospital, which said that registration for health IDs was mandatory for all the citizens of the country. The circular asked all heads of department to ensure that they registered themselves and had their staff and staff's family members do so within 48 hours. However, Dr Bir Singh Chavan, the director-principal, told me that there was no order by GMCH to mandatorily register and that only "the letter from DHS"—director for health services—"was circulated."

The medical superintendent and principal medical officer of the Government Multi Specialty Hospital in Sector 16, also known as GMSH 16, issued an order on 19 August, which said that registration was mandatory. The order asked all employees of the hospital and other civil hospitals in Chandigarh, and allied dispensaries, to get their respective medical facilities registered with the Digi Doctor and health infrastructure registries.

Paramedical workers on contract under the National Health Mission in Chandigarh, were also asked to create health IDs for themselves and their families. The NHM is the mainstay of India's public health system under which maternal and child care, communicable and noncommunicable disease control and other crucial programmes are run. A paramedical worker sent me a voice note which she said was from Dr Sangeeta Ajay, the nodal officer for the NHM in Chandigarh. The woman in the voice note can be heard reprimanding contract staff. "You all were given instructions to register yourselves and your health facilities as well but 1 am looking at the health portal right now and only one of our facilities has been registered as of now," she said. "I have just been scolded by sir, and I don't care how, but by the evening you all have to register yourselves, your facilities and all staff with the portal and then report back to me." I reached out to Ajay to confirm that she had sent the voice note but she had not replied by the time this story was published.

As the director of health services, Dewan supervises the functioning of GMSH 16, civil hospitals and dispensaries. He is also the director of the NHM in Chandigarh. I sent him a message asking why there have been instructions to healthcare workers to register themselves and their

families in the NDHM databases. He had not responded at the time this story was published.

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In my email to Gedam, I detailed the ways in which the Chandigarh health department was forcing healthcare workers to register themselves on the NDHM website. In his reply, Gedam maintained that all union territories had been asked to "ensure that no orders mandating participation in the National Digital Health Mission are to be issued, as the mission is designed to be purely voluntary in nature." Gedam also said that he had personally spoken to the director of PGIMER over the issue and "this fear of so-called non-compliance report appears to be unfounded."

"It feels like strong-arming really," a healthcare worker from the department of orthopaedics at the GMCH 32 said. "There is a hierarchy and we have to follow orders, even if they don't give it in writing, if your HOD asks you to register you have to register." The orthopaedics healthcare worker and two other doctors from the hospital said that they would not have registered for health IDs if it had not been mandated by their seniors. "They keep asking to give constant updates on how many members from our department have registered with the health ID, and so everyone has to ensure they have registered otherwise the HOD will know, and who knows what the repercussions will be," the junior resident who tried to register for three days said.

"If the healthcare staff in Chandigarh is being manipulated in these ways to register for the health IDs, then they are clearly under duress and compulsion and the scheme is being forcefully deployed," Raman Jit Singh Cheema said. Cheema is the Asia policy director and senior counsel at Access Now, a non-profit organisation that defends the digital rights of people around the world. He is also a board member of the IFF. "Even if on paper they claim something is not mandatory, there are regulatory incentives in place in government institutions saying that you better do something otherwise you will be penalised."

Cheema compared such regulatory coercion to what occurred with the Prime Minister's Citizen Assistance and Relief in Emergency Situations or PM CARES fund—a public charitable trust that was set up to set up to help people and businesses affected by the COVID-19 pandemic. Government officials were technically allowed to withdraw consent to donate a part of their salary to the fund, but only by asking for an exception from a senior official. "And that would be career suicide, because technically you can ask for an exception but then there are repercussions to face for that decision," Cheema pointed out.

Priya, a Chandigarh resident who goes by one name, told me that she had to register for a health ID at the GMSH 16 before she was allowed to go in for her antenatal check-up at the hospital. Hospital staff insisted that she provide her Aadhaar card details to complete the registration process. "They didn't ask me anything, nor did they tell me what this was for," she said. "There was a whole line of people there and they were asking all patients to register before going ahead for their consultation." She did not know whether the health ID was linked to her hospital records. She said her husband, who had a heart ailment and sought treatment at the GMCH 32, was also asked to register for a health ID before he was allowed to go for his consultation. "I guess the experience was ok for me because I was able to follow instructions and get registered quickly before going in for my check-up but there were so many others in the line who looked genuinely harassed," Priya said. "There are illiterate patients from rural backgrounds who didn't understand what was happening at all and were struggling to go through the process."

Amulya Nidhi, the national convenor of the Jan Swasthya Abhiyan—or the People's Health Movement—said that the NDHM should not be registering people for health IDs while the Health Data Management Policy was still up for consultation. "If the policy for protecting this data is still up for comment, then how can the government start this registration process either through a voluntary basis or through compulsion?" he asked. "At least ensure that policy is translated and disseminated in regional languages in the public before you dive into initiating the process."

Other members of civil society shared Nidhi's concern, asking why the NHA had initiated a pilot project before public consultation was completed and the document was finalised. "I raised the same question on my Twitter profile a few days ago," Singh, the disabilities-rights activist, said. "How are they even allowed to begin registering IDs when there are no policies in place for protecting sensitive health data?" The NHA extended the consultation period from 3 September to 21 September after a civil society outcry over the brief window that it had initially allowed.

Gedam defended initiating the pilot project stating that since no sensitive data had been collected yet, the project did not have to wait for the draft policy to be approved. "NHA has not collected any such sensitive information, does not need to or intend to collect such information," he wrote. "Only limited information like name, year of birth, state, district is being asked for the same." Dr SS Pandav, the nodal officer for implementing NDHM at PGIMER, echoed Gedam's words. "As of now, we are registering health IDs only and no sensitive data or health records have been collected yet," Pandav told me.

Mukhopadhyay, the IFF associate counsel, said that if there was no intention to collect personal health records, the government would not make people register for unique health IDs in the first place. "It is very disingenuous to try and separate those things, where you are trying to pretend that this registration stage is completely removed from what is to come after," he said. "All of this is part of the same process. Even at the registration stage, people are sharing their Aadhaar numbers. Such official identifiers are recognised as a form of sensitive personal data even under the government's Personal Data Protection Bill, but not under the NDHM Health Data Management Policy."

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For now, people have the option to either use their phone numbers or their Aadhaar cards to register for health IDs on the NDHM website. However, it is mandatory for doctors to produce their Aadhaar card for the verification process after registering as Digi Doctors. "The question to ask the government is whether these people whose health IDs were made were given a copy of the NDHM blueprint or the Health Data Management policy," Cheema said. He pointed out that without providing access to detailed information on what the mission entails, a person cannot truly give informed consent. "And even if the information required at this stage is not sensitive personal data, it is personal data. These are identifiers which can be used to link to any other data set on the individual," he said. According to him, Chandigarh authorities should have noted in their communications on the pilot that it was a voluntary effort for which they hoped health sector employees may consider volunteering and not subject them to duress as employer.

Nidhi dismissed the NDHM pilot project as an exercise which did nothing to improve access to healthcare in India. "In a country where the healthcare system is so unresponsive, and where people have to rely on the completely unregulated private healthcare sector, why would the government take up such a time-consuming and futile exercise in the middle of a pandemic?"

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