

On 14 September 2023 Dr Nicholas Crisp, who heads National Health Insurance (NHI) matters at the National Department of Health, provided the below responses to questions from Spotlight regarding progress with South Africa's new NHI-related data systems

Spotlight: Is the plan to build one national health data system, or several interoperable systems? Can you say something about what motivated the choice here between iterating on existing systems and starting something new from scratch?

NC: The plan is several interoperable systems. Our choice was motivated by following best practises.

Spotlight: How far are we along with building the new system? We understand that partly because of the EVDS system developed for COVID-19 vaccination, we now have a massive HPRS database, but what else has been built on top of that?

NC: There is no link between EVDS and HPRS, so we are not sure where the "understanding" comes from. EVDS data was managed through an extensive data protection agreement under the supervision of a standing Judge. The new systems being developed are going according to plan which has been communicated in several public forums. We presented the highlights at the PHASA conference on Sunday. (Crisp shared slides presented at the PHASA conference with Spotlight. You can see them here.)

Spotlight: Who is involved with building the new system? CSIR, NDoH, who else? Any private companies?

NC: There are standing arrangements with government entities with whom the National Department of Health (NDoH) are in partnership with to build the Digital Health platform. NDOH works with CSIR and many donor partners who have developed a range of legacy systems that need to be integrated. There are also various initiatives driven in provinces and we work with the private funders/providers in their initiatives.

Spotlight: Can you say something about the type of database frameworks and scripting/programming languages being used in the project? How open will the code be and who will own it?

NC: No, we cannot share this detail, but we can say that the code is owned by the National Department of Health in service of the people living in South Africa.

Spotlight: The Western Cape already has a relatively advanced system, and we understand that KwaZulu-Natal is working on something similar. Will these systems be replaced by the new NHI health information system or will they co-exist?

NC: We are working closely with ALL 9 provinces and the private sector to ensure that interoperability with various systems is enabled and support the vision of the NHI once the Bill (B) is promulgated into law (Act).

Spotlight: Then, we are also eager to understand how the system will work at various levels: Firstly the level of patient and healthcare worker accessing records to guide clinical decisions. Secondly, the use of health information at facility/sub-district/district/provincial level to help with quality improvement and management. And thirdly, the use of data for research. We will take them one-by-one in the below questions.

Spotlight: Is the objective to have a patient's information/medical history available at any facility in the system, providing of course the right permissions are in place for the staff accessing the data? Will patients have access to their data, [e.g.](#) through an app? Can you talk a bit about the objectives here and the related technical challenges.

NC: The intention is for users of the South African health care system to have access to their own medical data and that these users will provide the necessary permissions to relevant health care service providers to access their data at health establishments who are part of NHI. Clause 40(6)(b) of the Bill requires the Fund to ensure that the "information platform must facilitate portability and continuity of health care services available to users".

Spotlight: Currently a complaint we've heard from provincial level is that lots of data is being collected, but not everyone who needs access to that data at provincial or district level has access. There is a sense that data is flowing up, but not back down. Some people have suggested to us that the reasons for this are not technical and that they may partly be political or due to a misreading of POPIA. The suggestion is that these specific issues could be addressed without building a new system. What is your response to this?

NC: Firstly, this is a very vague 'general' comment and does not provide the context in which this comment arose. Data is shared through various existing systems which is aggregated data. Secondly, we urge the province to engage with us directly and not go to or through the media as this is counter-productive for the collaborative relationships and partnerships we are busy building. Lastly there are forums, like NHISSA, NHC-Tech and TWG (Technical Working Groups) that have been created to address such issues. The aim is for appropriate data to be available at every level of the healthcare system: Clinicians will see inside patient files, local, district, provincial and national authorities, researchers, etc will access aggregated data.

Spotlight: Under the new system, how will the data available to staff at facility/sub-district/district/provincial levels change from what it is now? Can you say something about what new technical capabilities will make these changes possible?

NC: Data will be made available electronically as opposed to the largely paper-based manner currently experienced. Data will always be of such a nature that better clinical decisions can be made to ensure that a healthcare service user receives the treatment they require. How the data will be accessed (i.e., what type of device etc) has not been concluded but the best solution will be presented.

Spotlight: While we have relatively good tracking of HIV and TB data, data on NCDs is not systematically captured in the public sector. How will the new system facilitate the better capturing of data on NCDs, especially diabetes and hypertension?

NC: The HIV and TB data are actually of concern because of parallel and legacy systems. There is also a problem that we do not just want 'HIV data' but rather to know about "people with HIV who also may have hypertension, be pregnant, and" so, the NDoH has embarked on building an EMR (Electronic Medical Record) with HIV and TB being the first module. There are plans to add new modules that focus on NCDs etc over the next period. The development and implementation of an EMR has been announced by the President of South Africa and therefore is a key deliverable of the Minister of Health.

Spotlight: As shown by the 'Better, broader, safer' report commissioned by the UK government, so-called trusted research environments (TREs) provide a technical solution that can help facilitate health research while also safeguarding personal data. The report makes a compelling case that TREs avoids much of the trade-offs between research and privacy inherent in the old data anonymisation paradigm. Will the new system being built in South Africa make use of TREs to facilitate research being done in the public interest? (For reference, the UK government report referred to above is here: <https://www.gov.uk/government/publications/better-broader-safer-using-health-data-for-research-and-analysis>)

NC: Yes, NDOH is aware and works with the UK government on a range of interesting projects. We are aware of several ways in which data is extracted to the public domain for wide access. The NDoH is engaging with all relevant stakeholders both public and private to ensure that the best health solutions be made available for the people living in South Africa. The NDoH has and will continue to engage with other countries to learn what they achieved in their countries and then apply and adapt them if found to be relevant for the South African context. Recently the NDoH embarked on establishing a TWG for Coding which comprised of public, private, universities and research groups with great success. This model works for the South African context and therefore is being adopted for other key decision points within the health care sector and NHI. (TWG = technical working group)