A PAN-ARAB PERSONAL HEALTH RECORD

Dr Mohammah Al-Ubaydli, CEO of Patients Know Best, tells Healthcare World Editor Sarah Cartledge about his recommendations to create a comprehensive record system

In 2020 around 41.4m people moved into or across Arab states . Notably, 35 per cent were from other Arab countries. And of 32.8m moving on, 44 per cent stayed in the region.

Moving a person without moving their health record raises the cost of healthcare. Doctors spend time and money recreating the record, and they can make mistakes without it.

For Dr Mohammah Al-Ubaydli, the CEO of Patients Know Best, the company behind Europe's largest personal health record platform, saving lives saves money. This situation is increasingly urgent as healthcare costs grow faster than economies do. A trained physician and accomplished author, Dr Mohammah has built his reputation as the leading personal health record provider to the world-renowned NHS. Now he has a proposal for a pan-Arab solution.

The current situation

Technology is now sufficiently advanced with increasing uptake to aim for a universal long-term solution. In the Gulf, the majority of care by most providers is documented digitally in an electronic health record. Saudi Arabia, Dubai, Abu Dhabi and Qatar already have shared care records between providers, and others in the region are scaling up.

These days, with a few exceptions, patients receive a copy of their data digitally. Gulf countries mandate it, having built national superapps during the Covid pandemic. These superapps include a copy of the record from across providers in a country. Providers also have patient portals as standard for onboarding customers and linking them to clinical care.

Furthermore, Middle East consumers are mobile-first and Middle East countries are global leaders in digital penetration. This local strength means they are ready for universal usage of technologies that have been proven at mass scale.

What is a personal health record (PHR)?

A personal health record (PHR) is a record about the health of a person, organised around that person. It is not tied to an organisation (as in a hospital or primary care portal), nor is it limited to a condition (like a disease app), and it moves with the person (not locked down to a region).

Importantly, a personal health record is the only architecture that supports the movement of data with the movement of people. This factor is vital not just for 41m Arab migrants - it is also key for native residents.

In the UK, it's estimated that 1 in 16 people has a rare disease , so they move to find specialists across regions. In addition, 50 per cent of healthcare spending is from 5 per cent of the population with complex conditions who often move between providers. The rare disease numbers are likely higher in the Arab region due to consanguineous marriages. As the Arab world's youthful population ages, the complexity and costs of care will rise.

Supporting the movement of data with people

There are three potential approaches to universal movement of data with people. First is a public sector top-down approach, with governments of the Arab world agreeing to work together. An alternative is a private sector bottom-up approach, but the public sector's laws and the private sector's incentives work against scale. The third is the public sector enabling the private sector, which has had successes in the region, and this solution is my recommendation.

MOHAMMAH AL-UBAYDLI
CEO
Patients Know Best

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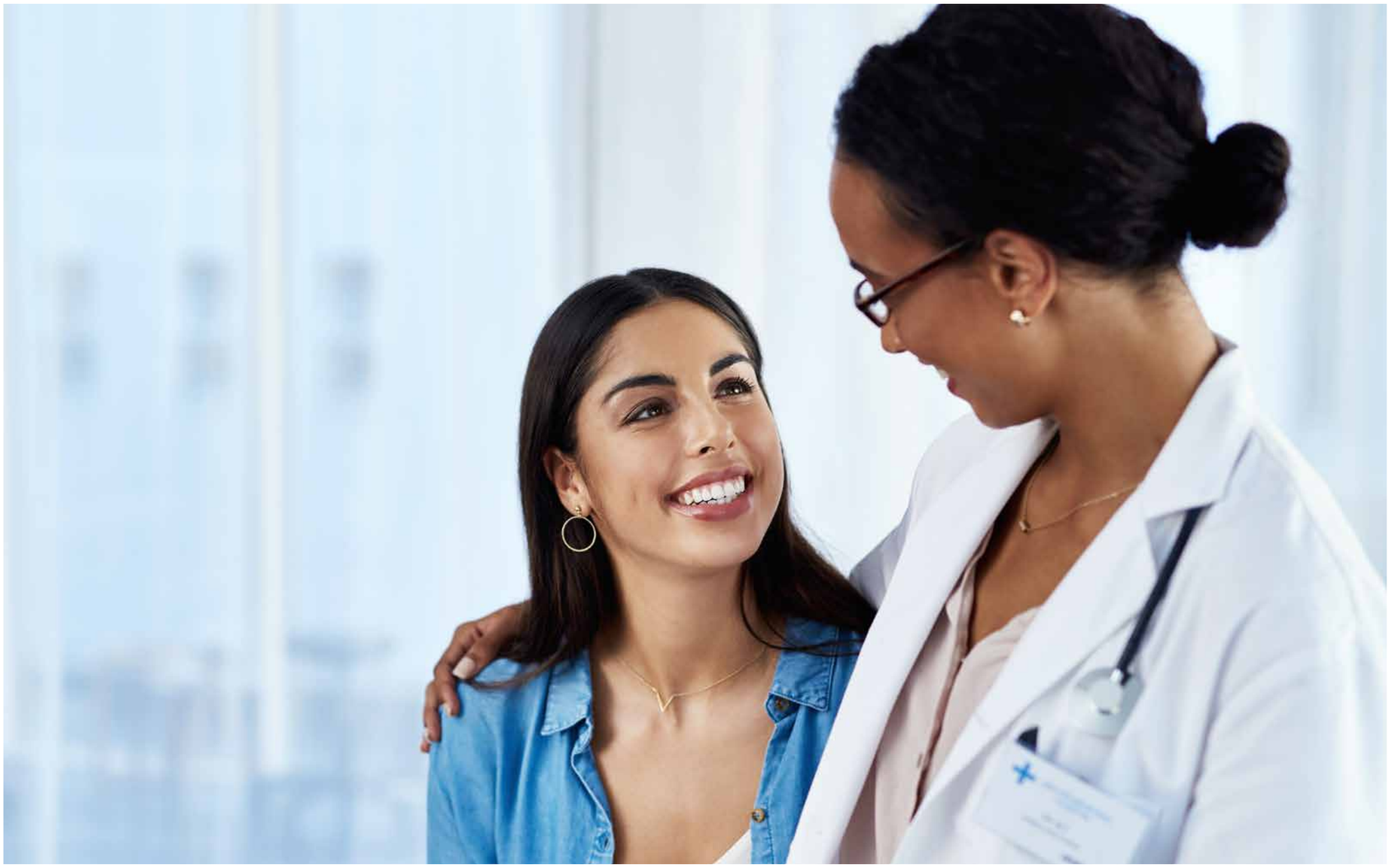

1. Public sector top-down

One path forward is to follow the European Union model, with mutual recognition by Arab states of their neighbours' infrastructure for storage. In 2022 the EU passed the European Health Data Space legislation. As a citizen moves from one country to another, the departure country's public infrastructure passes the citizen's data onto the destination country.

The GCC countries could lead the way in this approach through their existing practices of cooperation. At current speeds this will not be fast. Even with a political union and mature economies with cross-country wealth transfers, the European Union's progress has been slow. It took years for mutual recognition of data storage across the EU, still more years to agree to the EU Health Data Space legislation, and this in turn will take years to implement.

Elsewhere, ASEAN regional cooperation does not have a political union and does not have any of these elements. The African Continental Free Trade Area has only recently been formed. The Arab world's only free trade area is the GCC, although Bahrain and Kuwait's mutual recognition of data storage is the tiny exception that proves the rule. So at the moment, this route is not a reliable approach for public health.

2. Private sector bottom-up

The private sector has started down this path due to consumer demand. Hospital portals and apps attract paying consumers, and they expect access to data as part of routine care. However, the data is locked to the provider as, commercially, private providers do not like data portability because it allows consumers to shop around and move to other providers.

Legally, the GCC countries mandate in-country data storage. It is possible to have apps and portals that cross borders, storing data in each country and displaying it in one user interface on-demand. However, the behaviour of well-funded hospital chains operating in multiple countries has still been to silo storage and display by country as the providers want to avoid the regulatory risk of joining up care across markets.

3. Public-private cooperation

The model of a multinational personal health record app is definitely workable. Consumer-funded companies already cater to travellers who manually upload their medical records. And government-funded companies such as Patients Know Best already operate across multiple national jurisdictions.

If Arab nations cooperated with the private sector as the UK government has, then it is possible to scale such an option. The UK government opened up identity verification in England via the NHS login to the private sector and it is now reportedly used by 80 per cent of the population. The NHS App incorporates private suppliers to deliver features from electronic consultations to online appointment booking to personal health records.

The current UAE Pass has already shown that Gulf governments can also open up but, as yet, no Gulf country has yet opened up its national data stores to the private sector. Doing so would make their national app offerings dynamic, especially given the competitive marketplaces in the rest of their economies.

Governments do not need to fund these companies - this is simply a policy decision to allow the private sector to better serve their citizens and economies. Furthermore, as GCC countries kick-start this approach they can create national champions. The GCC countries are already standardising on FHIR 4, ICD and SNOMED CT for their national data sets. As the personal health records market starts in these countries, the companies will be well developed when other countries join this approach.

Such data portability also supports the life sciences industry. Given that 50-80 per cent of their residents are expats, the genetic diversity in the Gulf states' expatriate workforce makes it globally attractive for clinical trials.

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So what next?

This public-private cooperation proposal is put forward as part of global research on personal health records conducted by Dr Mohammah and his colleague, Federica Andreoni. The findings will be shared in a new book "Personal Health Records for Governments" to be published in December 2024.

If you would like to learn more about the research or participate in policy design, please contact ***book@phr4gov.org***

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