

Cross-border data sharing holds key to developing preventative healthcare system

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Big data and emerging technologies like AI hold the key to developing preventative-based healthcare systems globally, but first there are legal and regulatory hurdles to navigate, writes Charlotte Harpin, partner at law firm Browne Jacobson.

If moving from a curative to preventative system is the diagnosis for how we make healthcare more effective and affordable, then data is the medicine.

In particular, we need high-quality data and huge amounts of it if we are to develop truly actionable healthcare strategies, which may feature value-based payment models, population health interventions and precision medicine.

Mining data from a wide range of health providers, systems and patients helps to paint a more comprehensive picture. As does the ability to share this information across international borders, an issue highlighted by a new UAE-UK Business Council white paper, [Opportunities for collaboration between the UK and UAE in cancer care](#), which advocates for greater international collaboration in prevention, screening and diagnostics strategies for cancer care.

Successful cross-border partnerships depend on effective legislation and regulation to ensure privacy concerns, quality standards and commercial issues are properly considered. So how do we achieve this?

Covid-19 response illustrated benefits of harmonising frameworks

In June this year, Browne Jacobson joined a panel discussion exploring this issue at the HLTH Europe conference in Amsterdam alongside leaders from Swedish healthcare consultancy Skane Care, Portuguese health data analytics company Promptly Health and UK business analytics firm Lytix.

The General Data Protection Regulation (GDPR) illustrated how effective this can be. Introduced by the EU in 2016, it has become the standard-setter for data protection laws, with the UK enacting an identical UK GDPR since leaving the EU. The regulation has also become a model for laws in countries including Brazil, Japan, Singapore, South Korea, Sri Lanka, Thailand and the UAE.

This means we have partial harmonisation in core principles around how data should be shared, an issue that came to prominence during the Covid-19 pandemic as cross-border sharing of knowledge about the disease was vital to the effectiveness of treatment and vaccine development.

A collective determination to fight the disease globally meant countries were willing to temporarily put aside their national frameworks for the greater good.

Emulating this on a more permanent basis, rather than just as an emergency response, could hold the key to harnessing the benefits of data to advance healthcare across the world.

A single health record for the EU points the way forward

In this respect, there is lots of excitement building around the European Health Data Space (EHDS), the first common data space in a specific area to emerge from the EU's data strategy, and the EU AI Act, which seeks to regulate and enable positive benefit for society and healthcare from AI.

Approved in April this year and now being implemented, the idea behind the EHDS is to create a "single market" for electronic health records across the EU, enabling a free flow of data between countries within the union for research, innovation, policy-making and regulatory activities.

It also acts as a so-called "patient passport" by empowering individuals to take control of their health data.

The hope is that if it proves successful, its scope could be broadened to other jurisdictions, just as the EU single market signs trade agreements with other countries.

In the UK, data-sharing for research purposes is reasonably well established, but less so for cross-jurisdiction research.

This is fundamental in clinical trials as drawing people from different countries and backgrounds helps to secure a more diverse and representative pool of patients when testing treatment methods, doses or reactions to drugs, for example.

Across the world, there is a growing recognition that having a rich source of data enhances healthcare, whether it's in the way we develop treatments or technological solutions like artificial intelligence (AI).

Promptly Health, one of the companies in the HLTH Europe panel, is building an anonymised global data pool that researchers, software developers and pharmaceutical companies will pay to access.

Risks and regulatory considerations

Patient buy-in is crucial to the success of any project that requires their personal data to be processed. We must bring people along the journey with us and showcase the benefits while taking transparent actions at every step.

Sometimes we can overstate the restrictions that apply but it ultimately comes down to being very clear at the start of a project about how and where we want to share data, as well as why.

Data is very society-driven and various societies have different spectrums of concern about how data is used.

We can already recognise this in the divergence in approaches to AI regulation between the United States, which wants to harness its innovation potential with a light-touch regulation regime, and the stricter controls of the EU AI Act.

But where we can be harmonised – as the approach to GDPR demonstrated – is in having common understandings about the principles of data usage in order to maintain public trust.

One of the most sensitive issues relates to individual preferences and the right to "opt out" without sacrificing their access to effective healthcare.

Linked to this is ensuring that patients who are unable to access centralised data systems, such as patient passports, are not left behind due to factors such as language barriers, lack of digital literacy or the growing numbers of people experiencing digital poverty.

For those institutions that access and control health data, they must develop a culture of data compliance, supported by robust security mechanisms and managing access levels accordingly to different requirements.

Adopting these safeguards in partnership across jurisdictions can go some way towards ensuring health data can be safely yet effectively shared across borders for the greater good.

Key contact

Charlotte Harpin



Partner

charlotte.harpin@brownejacobson.com

+44 (0)330 045 2405

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