
NHS counters GDPR with millions-strong research dataset



In today's technology-driven world, data has become one of the most valuable commodities. And particularly in healthcare, the protection of personal data is of utmost importance. Just last month, the European Union introduced its new comprehensive data protection and privacy regulation, the General Data Protection Regulation (GDPR).

While GDPR applies to all data, its safeguards and building up of personal control of data will be especially important in healthcare, according to experts, who note that consent and trust in researchers using data is crucial if a "big data" and real world evidence (RWE) enabled healthcare is to become a reality.

In response to the GDPR, England's NHS announced its own "National Opt-Out" on the same day. Co-ordinated by NHS Digital, this new policy allows people to opt out of their confidential patient information being used for research and planning. These researchers could include universities, hospitals, medical royal colleges or be pharmaceutical companies researching new treatments.

There are approximately 55 million patients registered with England's health service. The hope is, of course, that most patients choose not to opt out, and allow their data to be used for research purposes. This is especially important for the NHS, as it holds what could be one of the world's most complete population-level datasets anywhere in the world.

With all the proper safeguards and patient consent in place, the UK government hopes to see NHS data serving as a world-class engine for research, attracting greater R&D investment and ultimately benefitting NHS patients as well.

"By gaining consent from NHS patients to use their health data, the UK stands to enhance its place as a world leading data-rich research ecosystem," says Naomi Boxall, Principal-Epidemiologist at IQVIA and specialising in RWE. "Increased global investment in clinical trials and real-world evidence studies would feed back directly into the economy and into NHS care."

This strengthening of UK data protection must also address fears about data leaks of highly sensitive medical records, however. The WannaCry ransomware cyberattack of May 2017 was a high profile example of the threat posed to NHS organisations. As such, it's important for NHS to invest in IT systems to maintain confidentiality and security, and communicate clearly how these safeguards work in order to allay fears.

"The opt out gives choice to people in a much more open way. I think this is a very positive step in the right direction – but it's just the start of a long conversation with patients and the public, not just about the benefits of using their data but also the risks," according to Chris Carrigan, expert advisor for UseMYData, a patient advocacy group.

Having this balanced conversation about benefits and risks means that the explanation of those benefits needs to be as compelling and clear as possible – NHS patients will need to be convinced that researchers using their data will be important and impactful – not just for them but all patients today and in the future.

Source: PMLiVE.com

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