

## Big data could benefit healthcare but raises privacy concerns

Written by Colin Mackay on 1 December 2015 in Opinion  
Opinion

New data legislation demands a delicate balance between the needs of the many and the needs of the one, says Colin Mackay.



The trilogue discussions on data protection and data privacy appear to be reaching a close. There is optimism of a concrete proposal emerging this year. However, the benefits and risks of using personal data splits opinion; nowhere more than in medical research.

'Big data' can digest previously unimaginable quantities of information, uncovering unforeseen patterns. This may address the challenges posed by chronic conditions such as heart disease or incurable illnesses like dementia and many cancers. Clearly, solutions to these problems would be universally welcome. However, the way forward is less clear.

This is because one of the richest sources of information is patient medical records. As we migrate to electronic formats, such data becomes simpler to extract. So simple, in fact, that patients have

understandable concerns that their anonymity may be compromised.

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UK ECR group member Vicky Ford has a constituency hosting both the European Bioinformatics Institute and the Genome Campus. She is understandably enthusiastic.

"The ability to process and analyse big data is key to developing next generation diagnosis, treatment and cures for many conditions like epilepsy, Alzheimer's and cancer," she said.

However, she sounded a note of caution; "We need to ensure that patients and society benefit and that data sharing takes place in a safe, secure manner that is also practicable for researchers."

Greens/EFA group MEP Jill Evans agrees. "There are challenges of data management and security that we must get right. Patient confidentiality should always be guaranteed and people must be confident that their medical information will not be shared inappropriately."

She stressed the need for balance; "Certainly, there is scope for sharing data from clinical and medical trials where relevant for policy decisions. But we must protect privacy by anonymising any data as appropriate."

Nicola Bedlington, Secretary General of the European Patients' Forum, also highlighted the delicate balance required in handling patient data. "Although there are clear benefits of sharing data, there are also risks," she said. "Individuals may have their health conditions inadvertently disclosed."

Designers of electronic health records (EHR) should consider the needs of users. "There must be a way to mask sensitive data or provide patients with control or information about who can access their data via EHR."

Patients already expect personal information to be treated confidentially. Katrín Fjeldsted, President of the standing committee of European doctors (CPME) believes, "this is the core of medicine and the basis for the trust between patient and doctor. Personal information must always be used ethically, safely and securely," she said.

Independent ethics committees and review boards would provide strong ethical safeguards and reliable governance structures, balancing, "the need for medical research to advance and the guarantee of public trust."

Cancer is an area that could benefit most from analysing patient data. Paolo Casali, public policy Chair of the the European Society for Medical Oncology, ESMO, advocates the concept of 'one-time consent'. This would allow patients to provide fully informed, withdrawable consent. They could donate their personal data for research purposes with strict safeguards.

For population-based registries, he argues for a derogation. "Such registries inform health policy and

have played a vital role in a number of medical breakthroughs. However, this is only possible if the registries are complete." Both positions had the endorsement of the entire European oncology community.

The healthcare industry is also following progress; pharma's interest in big data is well documented. It may benefit other sectors. Yves Verboren, Director of market access and economic policies at MedTech Europe, an alliance of medical technology industry associations, explains, "We already incorporate efficient ways of involving input from clinicians and patients, helping understand unmet needs," he said.

"Data from EHR may provide fresh insights, such as better understanding the impact of interventions and the effectiveness of care pathways." Tracking patient outcomes via EHR would help quantify the value of medical technology.

Given the potential impact, rapid agreement in the trilogue would be welcomed by all stakeholders. Healthcare costs are spiralling, and effective interventions to contain these costs will be welcome.

However, the need to balance the wider needs of society against the individual right to privacy cannot be avoided. Navigating a safe passage through these uncharted waters will not be easy.

## About the author

Colin Mackay is a Brussels-based writer and editorial consultant

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