

Rustam Gilfanov: Big data in healthcare, the ethical problem and its solution



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The coronavirus pandemic puts greater emphasis on the problem of digitalization for many, if not all, aspects of present-day life, with the healthcare industry being in the vanguard for obvious reasons. The amount of medical data that need prompt collection, processing, transfer, and interpretation saw a tenfold or even a hundredfold increase. Not only has this caused the workload of healthcare personnel to soar and revealed several similar issues, but it also demonstrated the vast opportunities MedTech can offer.

Here is the minimal, albeit incomplete, set of conditions for success. Firstly, the attitude to IT infrastructure must be professional, with products covering basic functional needs, leaving no gaps, and “speaking the same language” without any contradictions or overlaps. Secondly, proper implementation and support must ensure protection from potential black swans — unpredictable game-changing events. Thirdly, the ongoing personnel training and dialogue with patients need to be maintained. Finally, probably the most essential requirement is to work out an ethical code that is put to paper and

encompasses all business processes bar none. Successful MedTech startups all over the world, from Silicon Valley to the Dead Sea, have proved this approach to be the most effective.

Painful big data

Healthcare digitalization and optimized medical data management require a new, morality-based perspective. MedTech involves not only technical support and legal protection but also strict ethical and personal limits.

The reasonable attitude to personal data

The reasonable attitude to personal data is to treat them like body parts, i.e., taking good care and demonstrating them only to reliable and responsible people. As most people all over the world have not adopted this mindset yet, significant risks are posed for both patients and the professional community. In this case, healthy conservatism can be helpful, as it urges not to reveal personal information needlessly.

Patients will behave more consciously and responsibly when clear “printed” ethical codes appear and medics themselves improve their data literacy. Socially favored behavior will eventually be established for the digital culture; disregard for personal data will seem as embarrassingly downgrading as the habit of throwing garbage out of your window.

Medical, but no longer private

The ethical issue of implementing Big Data into the medical assistance system focuses primarily on medical privacy protection.

It must be noted that establishing a reliable infrastructure to meet all requirements and ensuring its protection is as important as protecting the information it contains. These two things are connected – that is what we learned, as we were working on Longgenesis, the tool for digitalizing biomedical research results. No matter how simple and logical a data management technology is, it will be completely useless unless it is properly protected against hacking and has a well-structured access system.

What's the treatment?

In theory, it is possible to use administrative funds and give computers with Internet access to all doctors and even patients – but the real problem is the mindset. Unfortunately, this mindset is shared by many in professional and civil communities, requiring a search for a consensus.

Summing up, it seems logical that ethical questions, including ones related to the IT industry, need to be addressed according to the three aspects: legal, technological, and social – with the latter being the most troubling one. Nothing can be harder than changing people's mindsets.

Healthcare is a very specific aspect of life that is human-oriented at its core. Setting goals for digitalization and following fashionable big data trends is not enough. At every step, we must ask ourselves: “on the personal level, how is it going to impact people?”. It is the matters of life and health that we are discussing here, so ethical and moral issues must be at least as important as technological approaches to healthcare modernization.

About the Author

Rustam Gilfanov is an IT entrepreneur and a venture partner of the LongeVC fund.

Media Contact

Blacklight

volodya.sidorov.2001@list.ru

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