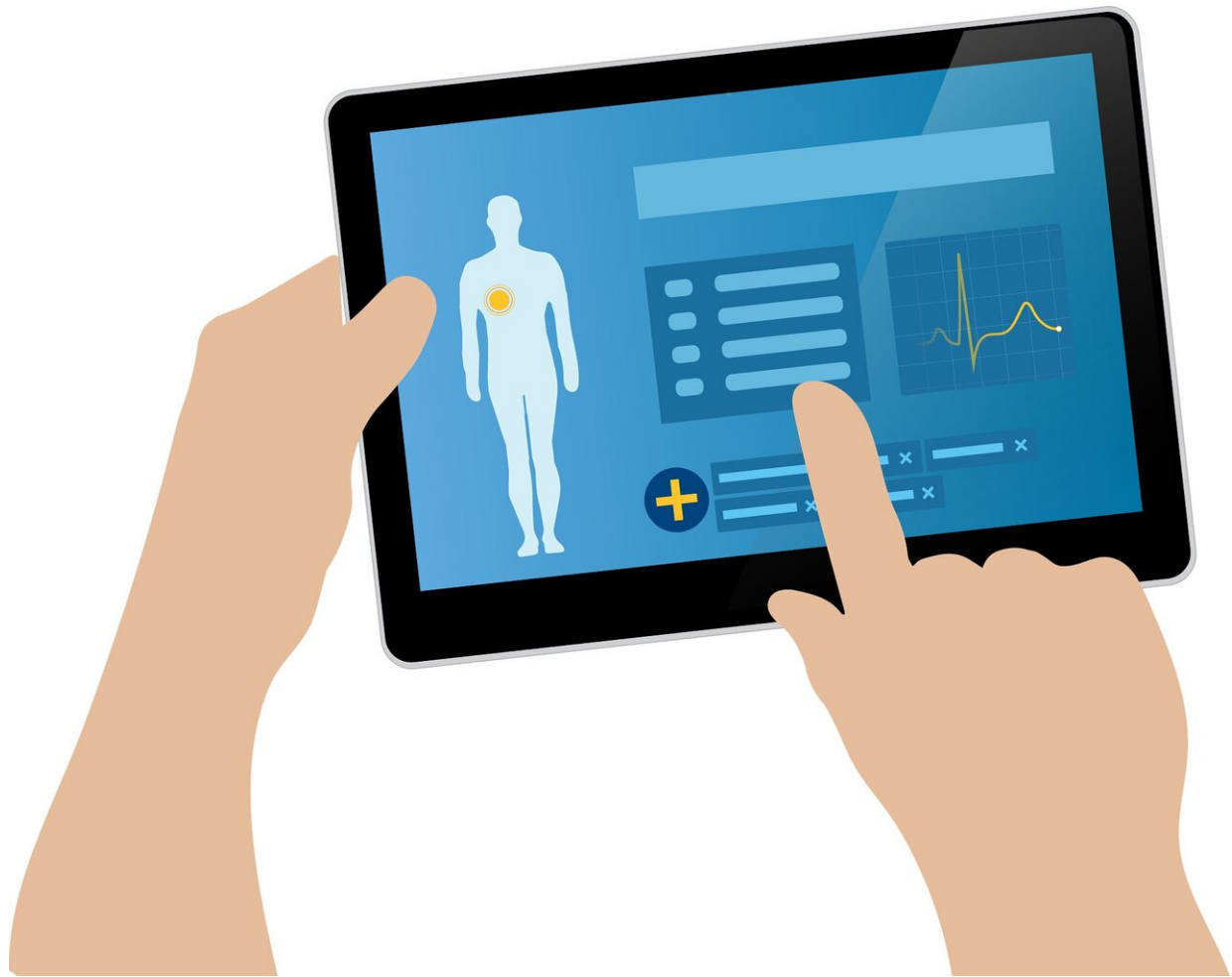


Patient notes could offer solution to the 'missing' coronavirus diagnoses

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GP's notes currently unavailable to medical researchers could provide clues to help manage major health crises—like COVID-19.

And according to a 'citizens' jury' study at Brighton and Sussex Medical School (BSMS), the main thing stopping the use of such [information](#)—concerns over [patient privacy](#)—could be overcome.

Lead author, Dr. Elizabeth Ford, Senior Lecturer in Primary Care Research at BSMS said: "In these times of a new and unknown disease like COVID-19, we really need all the health data we can get, in order to develop effective treatment quickly. For example, we've seen that the number of 'excess' deaths over the last few months doesn't tally with the number of actual deaths attributed to Coronavirus. Maybe information recorded by doctors during patient consultations could give us vital clues to understand these missing diagnoses?"

"Patient notes, letters and reports held within [medical records](#) contain a range of valuable information that is currently unavailable to researchers. Understandably, there are concerns about private details being made available for research but if we can find a way past that, research could benefit [public health](#) hugely. That's why we ran this study, and found that although they were cautious about privacy, members of the public were largely supportive of the information being made available to university researchers."

Currently the structured parts of patients' medical notes are used in an anonymised way for health research, helping to develop major improvements in health care. Until now, however, the patient notes, where a doctor might write a summary regarding a patient's visit, and letters and reports following scans or visits to hospital, have not been available for health research—largely due to concerns about protecting privacy. Advances in computer science and text analytics mean that researchers are now able to extract specific clinical information from

large quantities of patient documents and analyse many patient records at once.

During a three-day citizens' jury, 18 members of the public heard a range of expert presentations and arguments for and against sharing free text (from patient letters and notes from general practice and mental health care), and then questioned presenters and deliberated together.

Dr. Ford said: "Jurors were largely supportive of using patient notes and letters for medical research, but felt people had the right to know what their medical data might be used for, so they could choose to opt out. They also wanted to see a clear commitment to improving technology to protect patient privacy.

"While this was obviously a small study on a complex subject, the results show a public interest in making free text data available to health researchers. Next steps would involve a larger study to gauge wider public interest in how we might be able to make such health information available while protecting patient [privacy](#)."

The study is being published in the *BMJ Journal of Medical Ethics*.

More information: Elizabeth Ford et al, Should free-text data in electronic medical records be shared for research? A citizens' jury study in the UK, *Journal of Medical Ethics* (2020). [DOI: 10.1136/medethics-2019-105472](https://doi.org/10.1136/medethics-2019-105472)

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