Smile, you are being recorded. Almost all the time. On the motorway, in the mall, on the telephone with your insurance company, or asking Alexa to play Beyoncé. We don’t really know what happens to these digital mountains of data, but you can bet your bottom dollar that it’s making a few folks somewhere incredibly wealthy. Because what you choose to do, where you decide to go, or what to buy, are data about our preferences – and preferences get harvested, processed and interpreted. It’s the way of the commoditized world.

Recording has also made an appearance in healthcare: people are recording their visits, sometimes asking permission, sometimes doing so covertly. That more or less everyone has a telephone capable of taking digital recordings, using audio or video or both has transformed the ease by which this process can occur.

As is the case in many other areas of life, the ability of the law to keep pace with the implications of the increasing levels of surveillance is challenged. Our review of how the law deals with recordings by patients in multiple countries (pp. xx–xx, this issue) clearly illustrates that technological developments are outstripping our ability to design systems that can both guide behavior and ensure protection, where necessary, when recordings are made of sensitive information typically considered confidential and private.

We are grateful to our colleagues for their comments and views on the implications that are inherent in the review of the relevant laws, as provided in their rejoinders to our paper. Hyatt and Prictor (pp. xx–xx), researchers who have investigated the phenomenon of patients making recordings of healthcare encounters, ask how the law could better support the process, and therefore take the view that restricting this development is both impossible and perhaps counter-productive. Wynn and Ellingsen (pp. xx–xx) put the findings of our review into a Norwegian context, where there is no specific legislation for the situation where patients record their clinic visits. Hou (pp. xx–xx) describes the situation in Taiwan, a country that has clearly observed the desire by many patients to make recordings and share them with their family members. Clarke, Ballard and Doheny (pp. xx–xx) consider how recordings are relevant in the context of providing genetic counseling.

Hyatt and Prictor in particular describe the arrival of innovations, developed by academics and commercial interests, in this domain. They take the view that, despite the interest in the possible benefits of sharing the information contained in recordings, that the adoption of encounter recordings has ‘effectively stalled’, and that the primary reason for this is legal concern (p. xx). Their commentary confirms our view that the law is ill-equipped to deal with the technological developments in the realm of digital recordings, whether undertaken by individuals or by all manner of devices and organizations.
As they point out, there is legal opacity regarding every aspect of recording clinical encounters, encompassing initiation, storage, sharing and different use across multiple contexts. No legal system seems to have developed laws that can guide behavior around the increasing use of digital recordings, by many parties, in an increasing range of contexts. They correctly point out that the critical question that needs answering is: what legal developments are required to close this gap? Applying laws that were originally designed to address wiretapping or eavesdropping is inappropriate when everyone now has the means to easily record conversations, overtly and covertly, and increasingly wish to do so. The lack of relevant law leads to institutions writing policies that are misaligned, and often place restrictions that are both unenforceable and deny the benefits that could accrue to patients, clinicians and organizations.

Wynn and Ellingsen, in the context of Norway, conclude that a private individual may legally record conversations that he or she partakes in, both overtly and covertly, irrespective of the technical modality. However, once a recording exists, Norway has assumed the General Data Protection Regulation (GDPR) that arises from the privacy legislation of the European Union. Whilst the authors think that clinicians in Europe would likely agree to be recorded, they are not aware that this is occurring on a regular basis and do not seem to be aware that any organization is as yet offering routine recordings of patient visits. They conclude their rejoinder by suggesting that a way forward would be the acceptance that recording will increasingly occur and that a culture is developing in which it is expected that patients will ask permission and that clinicians will not deny such a request.

Hou describes a complex situation in Taiwan, where it seems that the delivery of healthcare has been occurring in a context of increasing levels of distrust. Where clinicians wish to make recordings, the law seems clear enough: the consent of the patient is required. However, whether or not the patient has the right to access those recordings is unclear. Hou does describe a situation in which an increasing number of patients are recording their visits, typically because they want to re-listen to clinical advice. This seems increasingly relevant for patients who have long-term conditions or are given complex information that they want to recall in more detail at home. Nevertheless, there are also instances in Taiwan where patients are recording covertly. The law in Taiwan, like in most other countries, is unclear about how to deal with this phenomenon.

Clarke and colleagues do not dwell on legal issues; rather, they examine the consequences of recordings for people who are seeking counseling on genetic issues. They raise the possibility that patients might not pay as much attention in the moment, and instead see the recording as something that they can rely on later. They think that having a recording in motion might push the patient to push the clinicians for more ‘definitive’ answers, or provide ‘clearer’ prognoses than would otherwise be the case. These seem to be speculations, and perhaps the task for the clinician is to become aware that their responses are likely to be reviewed, perhaps multiple times and by others. A recording, in this way, does perhaps amount to a more careful approach to information sharing. In the same vein, they speculate about how recordings would change the behavior of clinicians. For instance, perhaps clinicians might be more unwilling to raise a wider range of factors that could modify prognosis or progression.

Clarke and colleagues also consider the use of patient-initiated recordings for research goals. They describe the use of diaries in which the patient records their experience and reflections beyond the clinic visit itself. The issue of consent for the use of recordings in research, however, is very clear. Consent is always required and there are clear guidelines for the storage of data that becomes subject to analysis. The use of such recordings no doubt brings valuable data to research projects; this falls outside the scope of recordings initiated by patients in clinic settings.

And so what about healthcare? People are definitely recording their visits to clinics (Elwyn 2014; Hyatt et al. 2020), and it has led to debate (Elwyn and Buckman 2015). But in fact, some clinicians in the 1980s recognized the value of giving people recordings of their visits. Those were the days when the Sony Walkman made it easier to record, share and listen to conversations. It was oncologists and pediatricians who first realized the power of sharing recordings with their patients (Tsulukidze et al. 2014). When there was bad news to digest,
or complex information to try and remember, they realized that emotional situations drastically reduce cognitive capability, and so providing recordings was a clear way to help families understand what was happening to them. Patients and parents loved these recordings. They often listened to them multiple times. They shared them with family members, sometimes finding therapeutic solace in being able to playback the encounters (Tsulukidze et al. 2014; Wolderslund et al. 2017; Rieger et al. 2018).

However, although this trend started over forty years ago, very few clinicians adopted this approach. In the last few decades only about 30 studies of this type have been published (Tsulukidze et al. 2014), and they have not led to widespread adoption of this practice. The published studies clearly demonstrate a benefit to patients. Yet the idea has not caught on in any part of the world. As one can imagine, healthcare professionals and organizations had concerns: they were worried that making recordings of clinical conversations available brings too many risks.

Then the smartphone arrived, which offered people the ability to record at the touch of a button, even when the phone was tucked away, out of sight. At the same time, computers had begun to dominate doctors’ desks and, suddenly, their attention had to be split between a screen, a keyboard and the person seeking help. The computer made communicating with people much more difficult. Relationships frayed, and trust dwindled: doctors had to multitask under time pressure and complete more extensive notes. The result has been stress and burnout. Everyone has had to cope with more hurried conversations (Pieterse et al. 2019). Some patients saw the opportunity to use recordings. They clearly wanted to be able to listen again to recommendations that were perhaps laden with jargon and delivered at speed. Some asked permission to record their visits. Others, perhaps worried that their requests would be declined, started to record covertly (Elwyn 2014).

This phenomenon has led to a mixture of reactions (Elwyn and Buckman 2015). Many clinicians feel that this is the beginning of being placed under constant surveillance, perhaps motivated by bad actors who wish to complain or take legal action (Joshi et al. 2020). However, defense organizations that provide legal advice to doctors when things go wrong strongly support the idea of recording encounters. They take the view that there is no better defense against a complaint than a full transcript of what actually happened. Typically, healthcare management does adopt this approach. Most clinics develop policies that forbid recording, though a handful (so far) have embraced the idea, making the recording of clinical encounters a routine part of their service – a development which typically brings additional responsibility in terms of consent, storage and security. In the United States for instance, the Health Insurance Portability and Accountability Act applies to recordings undertaken by the provider institution (Elwyn et al. 2017).

The hope that there is a legal solution to this global phenomenon is unfortunately misplaced. In the US, the law is based on wiretapping statutes and varies from state to state. In most states, an individual has the right to record a clinical encounter if he or she decides to do so, either openly or covertly: the permission of the doctor or organization is not required (Elwyn et al. 2017). And as our review published in this issue (as well as Hyatt and Pictor’s rejoinder) reveals, legal systems across the world have not addressed how to provide safety rails to the reality that healthcare visits are being recorded and shared (Hyatt et al. 2020; Pictor et al. 2021).

Inevitably, there is increasing interest in the treasure trove of information contained in recordings of clinical encounters. What is being prescribed, by whom and for what condition? Is it possible to alert clinicians to diagnoses using voice patterns? How are clinicians performing in relation to clinical guidelines? Are patient outcomes better if recordings are shared? How are clinicians communicating with patients, and can this be improved (Ryan et al. 2019)? These are just some of the use cases and interests that can be imagined if access to such recordings becomes possible.

Another use that is becoming increasingly possible is to relieve doctors and care systems from the oppressive burden of documentation. One of the pioneers in this area is an American company called Abridge (www.abridge.com). This increasing burden is largely responsible for high levels of clinician burnout, where the task of entering notes into computers and completing mandated data fields is becoming unsustainable (Gaffney et al. 2022). Innovations in speech and speaker recognition,
machine learning, clinical summarization and automated clinical coding are tantalizingly close to allowing doctors to escape the constraints imposed by screens and keyboards, to focus more on eye contact and communication skills.

So, we are left with urgent questions: is the recording of clinical encounters becoming viewed by doctors as surveillance or as deliverance from the arduous task of keeping detailed notes? Is this the future nightmare of a panopticon system, where a dreaded recorder sits on every desk? Or is it a technology that is widely embraced, because it delivers as much value to doctors as it is already known to provide to patients?

Declaration of interests

Glyn Elwyn has provided advice to a number of academic groups and to Abridge about how to support the use of recordings in healthcare contexts.

References


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