

Citizen generated data: the ethics of remote patient monitoring

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Digital technology is changing the way health systems care for patients. Citizen generated data from digital devices, apps and home sensors can be used outside traditional healthcare settings to monitor aspects of a patient's condition allowing healthcare professionals to track health trends over time.

Remote patient monitoring platforms can predict imminent adverse events, promptly alert caregivers, and facilitate earlier interventions. The benefits for patients include empowerment through better understanding and management of their condition, resulting in better clinical outcomes and less use of NHS and social care resources. However, these platforms raise a number of ethical considerations around the collection and use of this data. These need to be mitigated if remote patient monitoring platforms are to be implemented effectively.

Key points

- Remote patient monitoring is a new model of care that utilises <u>citizen generated data</u> and requires the active participation of patients to share data with the health system to support their care
- Platforms used for remote patient monitoring rely on the standardised collection of high quality data to benefit patients and health systems. These benefits are contingent on devices, tools and analytics being valid, accurate and clinically useful
- Ensuring that potential harms such as the perpetuation of health inequalities and patient privacy concerns are mitigated will be important for the wider implementation of this type of care model
- The clarification of relevant professional responsibilities will enable healthcare professionals to make full use of remote patient monitoring data
- More research to establish the clinical impact of these devices is essential as well as initiatives to actively support and collect feedback from patients using these devices



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Remote patient monitoring in use

Collaborations between the NHS, researchers and developers are exploring the use of remote patient monitoring platforms for a range of applications. These include:

- Monitoring by healthcare professionals: A trial at Papworth Hospital uses machine learning to analyse device data submitted by cystic fibrosis patients to predict impending infection or symptom exacerbation, prompting clinical assessment
- Monitoring within care relationships: NHS test bed <u>Care City</u> uses a range of personal and environmental monitoring to track elderly patients in the home, predict the likelihood of falls and alert carers to patients wandering beyond a predefined safe zone
- Self-monitoring initiated by health professionals: MyCOPD is an app which patients with Chronic Obstructive Pulmonary Disease can use as a self-education tool to help them manage and control their condition by monitoring symptoms over time. Patients can opt to share their data with healthcare professionals for additional support

Harms arising from over-reliance on data

Whilst remote patient monitoring offers clear benefits, potential harms could arise. Overestimating the capabilities of devices could lead to patients and/or healthcare professionals over-relying on data, potentially fostering a false sense of complacency should the technology not detect a problem. This may result in missed diagnoses and delayed intervention. Conversely, overdiagnosis could lead to unnecessary health anxiety for the patient – for example if monitoring devices detect changes that are no cause for concern.

Lack of clarity around professional responsibilities

Remote patient monitoring may lead to overdiagnosis and overtreatment if healthcare professionals err on the side of caution and intervene when there is uncertain clinical utility. On the other hand, lack of clarity surrounding professional responsibilities and guidance on how it fits within current patient pathways could deter clinicians from engaging with remote patient monitoring. Although less likely to arise as an issue in the context of pilot studies on small cohorts, if remote patient monitoring is scaled up without substantive guidance and clarity of responsibility, clinicians may be reluctant to utilise this data to guide clinical decision-making.

People cannot be reduced to their data

Over-reliance on data could facilitate reductionism – data from monitoring devices cannot tell the observer anything about the person's mental or emotional state, or the context in which the data was recorded. The benefit of a reduction in time-consuming face-to-face interaction with the health service could be at the cost of gaining contextual data and more subtle cues during consultations – for example, a doctor may notice the patient looks unkempt, prompting them to ask about their mood and wellbeing.

Health inequalities

There is potential for remote patient monitoring to perpetuate health inequalities. These platforms require the use of digital technologies, and will tend to favour patient users who have higher levels of health activation - who prioritise their health and have the interest, skill and literacy needed to be able to engage with it.

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Not all patients will be willing and able to use such digital devices, and studies show that there are disparities in populations that use digital tools¹. The reasons for this include a lack of reliable access to internet or mobile technologies; disinterest in one's own health; or discomfort using these technologies. This could lead to patients who are unable or unwilling to participate missing out on clinically relevant insights that can be derived from that data, and as a consequence, the need for more frequent interactions with healthcare, more trips to hospital, relapses and adverse events over their life course.

Privacy

Digital technologies have transformed our ability to collect and analyse large amounts of data about individuals and their health, raising concerns around the erosion of privacy. The right to privacy protects people from unwanted intrusion into their personal lives and is an important pillar of medicine. Various types of privacy exist; in this context the division of privacy into 'physical privacy' (the right to possess and protect personal space) and 'informational privacy' (having control of data about oneself)² is relevant.

Home monitoring systems

Home monitoring systems potentially infringe upon multiple aspects of a person's privacy. Employing connected sensors and devices that can feed back to the health system (e.g. Care City, above) is justified on the basis of their potential to minimise adverse events and increase the autonomy of elderly individuals or those managing long-term conditions.

Such systems often involve a range of integrated sensors that capture data which is sent to and assessed by a third party caregiver. Whilst some may find home monitoring reassuring, others might find its pervasive nature engenders a sense of 'being watched' even where no one is reviewing the data. Notably, this vulnerability to observation may in itself be harmful, even if no observation occurs. Studies suggest, however, that those with chronic conditions view the benefit of rapid access to information as outweighing privacy concerns³.

These privacy losses are exacerbated by the fact that privacy policies are often inaccessible and rarely revisited. Where data from multiple sensors are processed through complex analytics, it can be unclear what data is collected and for what purpose. Patients therefore need to understand the use of their data, the limits to this use, and the inferences which can be made from it. Whilst communication of new care models can work well in trials, the dialogue between researcher and patient should be maintained when remote monitoring is implemented more widely.

The commodification of privacy

Many platforms, devices and apps that patients engage with, although increasingly part of the 'digital architecture' of the health service, are produced by commercial entities. In order to use these technologies consumers have to consent to commercial terms of use which often permit the company to sell users' health data to third parties.

Mere acquiescence to pre-dictated 'terms and conditions' rather than properly informed consent could encourage users to see health and privacy as commodified benefits for the exchange of personal data. Due to this 'trade-off', many feel it is impossible to limit access to their data, and instead see digital profiling as inevitable.

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Policy considerations

To address the challenges outlined in this policy briefing, measures could be taken to:

- Enable healthcare professionals to make full use of remote patient monitoring data by clarifying professional responsibilities around reviewing this data and incorporating it into clinical decision making
- Continue with NHS initiatives (such as <u>Widening Digital Participation</u>), so that digitally excluded groups can benefit from digital health training
- Ensure that patients using digital health devices have ongoing opportunities for dialogue with the health system concerning their use of devices, including opportunities to renew their consent and revisit privacy policies
- Encourage more research to establish the clinical impact of utilising these devices to inform disease management

Remote patient monitoring systems are a great example of where the health system is actively engaging with citizen generated data. There are clear benefits to be gained by harnessing data generated by patients outside clinical settings and the efforts so far have been positive. These considerations are relevant to those implementing new remote patient monitoring platforms and scaling up existing provision.

References

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- 2. Mittelstadt B. <u>Ethics of the health-related internet of things: a narrative review</u>. Ethics and Information Technology 19(3), (2017)
- 3. Hale TM and Kvedar JC. Privacy and security concerns in telehealth. Virtual Mentor. 2014;16(12):981-985

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PHG Foundation is a health policy think tank with a special focus on how genomics and other emerging health technologies can provide more effective, personalised healthcare

