

Chapter 69

The Ethical Implications of Personal Health Monitoring

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ABSTRACT

Personal Health Monitoring (PHM) uses electronic devices which monitor and record health-related data outside a hospital, usually within the home. This paper examines the ethical issues raised by PHM. Eight themes describing the ethical implications of PHM are identified through a review of 68 academic articles concerning PHM. The identified themes include privacy, autonomy, obtrusiveness and visibility, stigma and identity, medicalisation, social isolation, delivery of care, and safety and technological need. The issues around each of these are discussed. The system / lifeworld perspective of Habermas is applied to develop an understanding of the role of PHMs as mediators of communication between the institutional and the domestic environment. Furthermore, links are established between the ethical issues to demonstrate that the ethics of PHM involves a complex network of ethical interactions. The paper extends the discussion of the critical effect PHMs have on the patient's identity and concludes that a holistic understanding of the ethical issues surrounding PHMs will help both researchers and practitioners in developing effective PHM implementations.¹

INTRODUCTION

The conjunction of wireless computing, ubiquitous internet access and the miniaturisation of sensors has opened the door for technological applications in medicine which allow the remote monitoring of medical conditions and relevant physiological parameters. Such technologies, examples of which

are given in Table 1, come under the heading of personal health monitoring (PHM).

PHM refers to any electronic device or system that monitors and records data about a health-related aspect of a person's life outside a hospital setting. To qualify as PHM a device must be capable of transferring data to a third party and be usable by a layperson outside a traditional medical environment such as a hospital. PHM is related to

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Table 1. Personal health monitoring technology examples

<p>Blood pressure monitoring - A patient with hypertension can use a wrist watch style device which monitors their blood pressure (BP) on a 24/7 basis (Laurance, 2011; Milenkovic, Otto & Jovanov, 2006). The monitor can create a log of fluctuations throughout the day, and can automatically alert the user to heightened BP. The data can be analysed alongside a log of the user's behaviour throughout the day, which may reveal the effects of particular activities, foods, medications and other factors on the user's BP. This information may be usable by medical professionals to create a personalised treatment or lifestyle plan for the user.</p>
<p>In-vivo blood monitoring - Patients with a wide variety of disorders detectable through blood tests can make use of an in-vivo system which monitors blood quality in real time (Gaul & Ziefle, 2009; PositiveID, 2011; Pousaz, 2013). Possible uses include real-time blood glucose monitoring for diabetics, or early warning of heart attacks from the presence of indicator substances which appear in the blood immediately before an incident. The effect of medications could also be tracked in real-time, leading to more personalised health interventions.</p>
<p>Smart home monitoring - Homebound chronically ill and elderly persons can make use of smart home technologies, which can detect behaviour and health parameters through sensors installed in the home (Chan, Campo, Estève & Fourniols, 2009). Sensors could detect sleep patterns, activity levels, falls, and emergencies and automatically alert family members or medical professionals when an emergency occurs, or a problematic health or behaviour pattern emerges. The effect of medications could also be tracked through behavioural data. Information gathered by smart home sensors could be used to evaluate the care needs of 'at-risk' patients, and keep a 'watchful eye' on them when human carers are unavailable, which supports ageing at home for longer than would be possible without such monitoring.</p>
<p>Wearable sensors - 'Smart clothes' capable of measuring heart rate, respiration, body temperature and other physiological parameters could aid athletes in training and physical competition (Lymberis & Gatzoulis, 2006; Milenkovic, Otto & Jovanov, 2006). Emergencies and physical limits could be detected with precision.</p>

'telehealth and telecare' (Kaplan & Litewka, 2008) and 'assistive technologies' (Demiris & Hensel, 2009; Tiwari, Warren, Day & McDonald, 2010), and covers various technologies including 'ambient intelligence' (Kosta, Pitkänen, Niemelä & Kaasinen, 2010), 'somatic surveillance' (Monahan & Wall, 2007), 'wearable health sensors' (Arnrich, Mayora, Bardram & Tröster, 2010; Lymberis & Gatzoulis, 2006) and medical 'surveillance technologies' (Niemeijer, Frederiks, Riphagen, Legemaate, Eefsting & Hertogh, 2010).

The applications of PHM are wide, and can include physiological monitoring in healthy people, for example, for monitoring the body's response to sports activities (Ganti, Srinivasan & Gacic, 2010; Monahan & Wall, 2007). The primary focus of PHMs, which will be pursued in this paper, lies in the support of patients with long term chronic conditions such as chronic pulmonary obstructive disease, diabetes, asthma and heart disease (e.g. De Toledo, Jimenez, del Pozo, Roca, Alonso & Hernandez, 2006; PositiveID, 2011; Ure, Pinnock, Hanley, Kidd, McCall Smith, Tarling et al., 2012). Such conditions often require long stays

in hospital or hospitalisation at short notice. The use of PHMs may help patients to stay at home and live a more normal life outside the restrictions of institutionalisation (Empirica & WRC, 2010; Remmers, 2010; van Hoof, Kort, Rutten & Duijnste, 2011). PHMs may also appear attractive to hospitals looking to reduce costs and free up hospital beds (e.g. Henderson, Knapp, Fernandez, J.-Beecham, Hirani, Cartwright et al., 2013; Lomas, 2009).

However, moving patients to their homes and implementing PHMs to enable monitoring by the hospital or clinicians changes the dynamic of the relationship between the patient and the hospital/clinicians, embedding aspects of medical institutions into the patient's home environment (e.g. Palm, Nordgren, Verweij & Collste, 2012). Interventions may be done remotely and large amounts of medical data may be transferred from the home to the hospital or clinician. This may result in what Habermas (1992) terms the 'colonisation of the lifeworld' in which the private concerns and activities of the patient become the concerns of the public institution which draws

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