

**Patient Generated Health Data in Ireland: A Study of the
Patient Perspective**

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Declaration

I declare that the work described in this dissertation is, except where otherwise stated, entirely my own work, and has not been submitted as an exercise for a degree at this or any other university.

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Abstract

Introduction

In today's healthcare setting, the most common and recognised form of medical information is that which is generated by healthcare professionals about patients under their care e.g. investigation results, observations, notes etc. However, there is also a second, highly valuable source of data known as patient generated health data (PGHD). This is data created or gathered by patients or their family/caregivers about their state of health. While it can often be the same type of information generated by healthcare professionals, the process of collecting the data typically happens outside of medical appointments, for example in the home. There is increasing interest in the potential for this data to inform treatment plans, personalise healthcare and to motivate patients to self-manage their conditions. The latter is particularly pertinent in the case of chronic diseases, where patient engagement is widely touted to be a key factor for effective healthcare management. Despite the fact that patients are essential in the capture and sharing of this data, to date much of the research on PGHD has been from the perspective of the healthcare professional. The aim of this study is to investigate and report on the patient perspective.

Methodology

An in-depth literature review of this topic was performed, after which it became apparent that patient views on PGHD are less well understood. Therefore an inductive, exploratory investigation into the experience and views of a set of chronically ill patients in the Irish healthcare setting was chosen as a basis for this research. A semi-structured interview was designed as part of this study and 8 participants, with varying chronic illnesses, were interviewed during April 2017.

Results

Participants represented a range of chronic illnesses and ages. In general, the study found that patients are willing to engage in the capture of PGHD if requested to do so by their clinician or if they feel that it will inform and improve their treatment plans. While all participants reported benefits, there were also challenges related to ongoing motivation/engagement, security and confidentiality, lack of methods for sharing data, and a complex patient-clinician relationship.

Conclusion

While the study population for this research was relatively small, it allowed for in-depth investigation with participants. This was particularly important given the imbalance between a lack of studies related to PGHD from the patient perspective and the increasing focus on the ability for PGHD to reduce the burden on the healthcare system. This study contributes to the knowledge base by providing insight into the views and concerns that patients have with respect to capturing and sharing health data. Further acknowledgement of the importance of the patient's role and views on this topic is necessary if PGHD is to be successfully integrated into clinical care pathways and electronic healthcare systems.