



**Trinity College Dublin**

Coláiste na Tríonóide, Baile Átha Cliath

The University of Dublin

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

by Katie O'Rourke (2017)

**Research Methods**

**Group-I**

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# Research Question

*“To investigate the experiences, views and expectations of a cohort of individuals living with a chronic disease, with respect to the capture and sharing of patient generated health data.”*

Source : **O'Rourke, Katie** (2016/17)

M.Sc. in Health Informatics

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

## Few of the research aims mentioned

The purpose of this research is to:

1. Review the literature to ascertain what is already known about this topic from the patient's viewpoint,
2. Use this knowledge to inform an exploratory investigation into the experience and views of a cohort of chronically ill patients in the Irish healthcare setting and
3. Report on findings.

# Research Aims

- Study patient's perspective on PGHD (Patient Generated Health Data) in Ireland
- Study aspects like - willingness, expectation, motivation, concerns from a patient's point of view
- How PGHD can be incorporated into patient's treatment
- Review the available literature on PGHD
- Target a wide range of chronic diseases for study of PGHD
- Study role of technology in collecting and sharing PGHD, study the awareness among patients about the use of such technology
- Report on all findings

# Design plan

- Literature review
- Ethics approval (9.5 weeks!)
- Participant recruitment process  
Opportunistic/Convenience methods
- Interview structure  
Exploratory, Evolving with time
- Data Analysis  
Hybrid deductive-inductive approach  
Identification & Clustering of themes

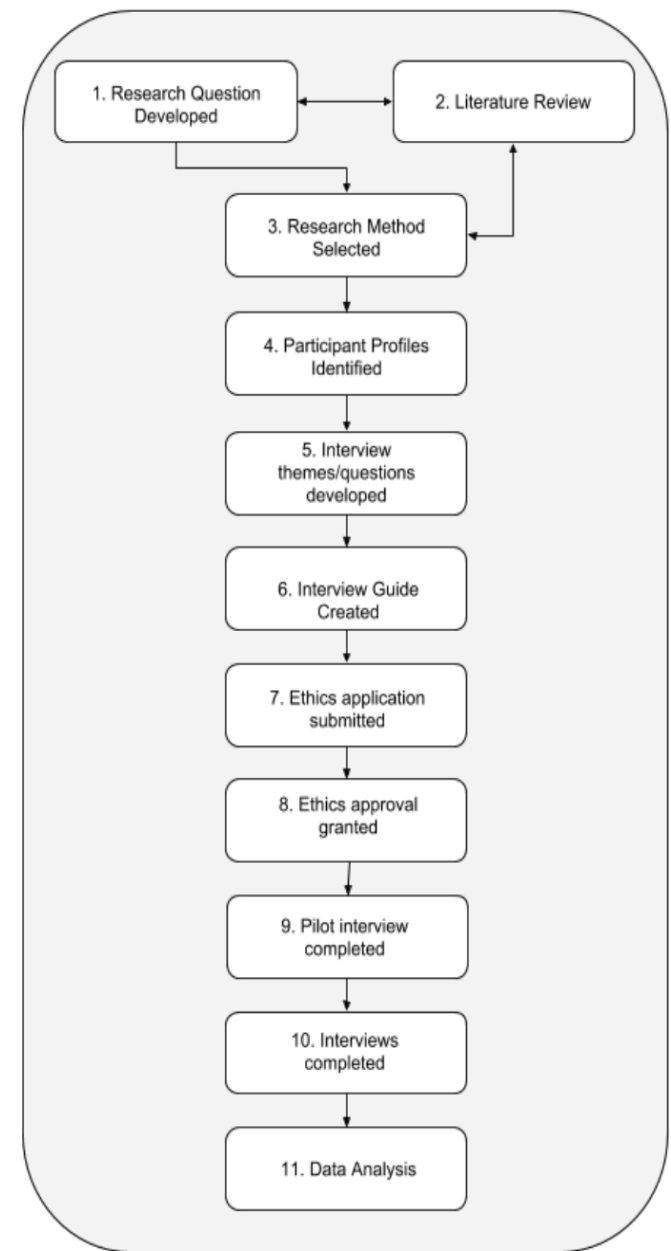


Image Source : **O'Rourke, Katie** (2016/17)

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3.1: Methodology Development Process

# Criticism

## Positives:

- Provides a good base for future research from a patient perspective [also from doctor's perspective, why PGHD is not studied by the institutes?]
- The research scope was kept small but it was carried out in a structured manner
- Provided references and cited them wherever needed

## Negatives:

- All the research aims mentioned initially were not fully addressed
- Could have been planned better which could have resulted in more conclusive findings [Ethics application could have been applied earlier]
- More questions could have been asked to gain insight on some findings [If the user is tech savvy or not] [Awareness/Opinion on mHealth apps] etc.

# Initial research aims

## 1.3 Research Question

This aim of this study is to address the following research question:

*"To investigate the experiences, views and expectations of a cohort of individuals living with a chronic disease, with respect to the capture and sharing of patient generated health data."*

In order to do this, the research question is broken down into the following:

1. What are the ways in which patients currently capture health related data in an electronic format? How are they collecting it in non-electronic formats and what can we learn from this for electronic capture of data?
2. What are the motivations behind patients capturing PGHD?
3. Are patients willing to share, or not share, this data with their medical team? Why?

## Does not conclusively answer most questions presented above

While this study has not conclusively answered any of the research questions, it has provided insight that can be built upon through additional work and adds to a body of knowledge related to PGHD by addressing an area which to date has not been the subject of substantial focus. The patient view needs to be an area that is further looked at and understood if the call to have a more engaged patient population, particularly for chronic illnesses, is to become a successful collaboration rather than an exercise in words.

Snippets from : *O'Rourke, Katie* (2016/17)  
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# Improvements

- Improve and scale recruitment process  
[Try to connect with several healthcare centres]  
[More focus on opportunistic/convenience methods]
- Two set of interview questions: Short & Open-ended type  
[Depending on the interviewee's mood]
- User-group specific interview questions  
[age-specific, chronic disease specific]
- Iterative interview cycles  
[Restructure questions based on results]



# Group Contribution

- 1. Each team member read the dissertation.**
- 2. Each team member provided their individual insights and review of the paper which were later on consolidated during group discussions.**
- 3. Each member contributed in the final presentation with each focusing on sections as mentioned below:**
  - Swastik Sahu: Individual review, Criticism, Interview structure, PPT
  - Ashutosh Sharma: Individual review, Research Aims, Ethics, PPT
  - Roman Shaikh: Individual review, Improvements, Grammatical errors
  - Udit Retharekar: Individual review, Methodology/Design Plan, Citations
  - Sahir Sharma: Individual review, results and findings, PPT

# Any Questions?



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Thank You