

# **PhD projects Greater Manchester Connected Health Cities**

**PhD studentships available to start from April 2017/September 2017**

## **Greater Manchester Connected Health Cities Programme**

**Project 4: How can we develop a new social licence for the commercial use of health data in the North of England?**

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### **Background**

The commercial use of health data is a controversial topic for many people. There has been a consistent message from multiple studies that many members of the public do not support the idea of commercial companies making money (particularly if it is seen as excessive amounts of money) from using “their” data (Wellcome Trust, 2016). The pharmaceutical and insurance industries are particularly disfavoured. However, some of the desired outcomes for the Connected Health Cities investment involve industry partnership and business and economic growth, which require the commercial use of health data.

A social licence can be seen as the expectations of society regarding the conduct and activities of companies and organisations that go beyond the requirements of formal regulation (Carter et al 2015). In the context of the secondary use of data, the conditions for social licence has been argued to include: “(i) reciprocity, which must begin with sound two-way communication, (ii) nonexploitation, which must exclude the spectre of disempowerment, and (iii) service of the public good, which need not exclude a wealth agenda so long as there is confidence that research governance and information governance systems can hold researchers, and others with custodial responsibility for medical information, to account” (Carter et al 2015). However little is known about public engagement should be done to ensure delivery of a new social licence around the commercial use of data.

### **PhD project outline**

This PhD programme of study will explore further details about variations in public opinion around this area and investigate ways in which it might be possible to gain public approval for such use of data, using a mixed methods design. This work will be underpinned by the ongoing work of Connected Health Cities (such as the citizens’ juries and discrete choice experiments) and the Farr Institute (such as the proposed comparative discrete choice experiment in Scotland and Sweden). There will be three distinct work packages:

- 1 systematic review of what is known about how the public attitudes to, and social licence for, the commercial use of health data can be measured

2 development of a method by which changes in social licence among the public can be measured over time

3 empirically tested comparison of different ways to present information about commercial uses to the public and how this affects the social licence, based on theoretically informed, but as yet untried, recommendations from the Wellcome Trust

**Student Background required:** This research will particularly appeal to students with a broadly social sciences background, but those with an epidemiology, health services research, psychology or clinical background are welcome to apply.

*Ipsos Mori & Wellcome Trust. The One-Way Mirror: Public attitudes to commercial access to health data. The Wellcome Trust, London. 2016*

*Carter, P., Laurie, G. T., and Dixon-Woods, M. The social licence for research: why care.data ran into trouble. J Med Ethics 2015; 41(5): 404-409.*

**CLOSING DEADLINE: FEBRUARY 17<sup>th</sup> 2017**