



The Church of Scotland

Church and Society Council

Surveillance and Social Justice – May 2017

Section 16. Bio-data

16.1 Datafication can save lives and our theological framework encourages us to affirm important acts of care. Physician John Snow's information gathering in London in 1854 enabled him to understand that cholera was water-borne rather than air-borne. Sir Richard Doll's informal observations in Oxford of cigarette smokers developing lung cancer led to later painstaking statistical testing that established a causal link. Records stored for one purpose can, perhaps years later, be of use for a totally different purpose. It is possible that had there been a robust programme of post-marketing surveillance in place when the drug thalidomide ("distival") was licensed in 1958, the correlation with birth defects might have been identified earlier and the drug withdrawn sooner than 1962.

16.2 Early intervention to prevent a genetically-transmitted disease occurring may be counselled within NHS support systems. However, there are also commercial companies who offer genetic testing for a wide range of genes known to be implicated in a variety of diseases. Ease of collection of DNA samples (e.g. a hair bulb or smear of cells from inside a cheek) raises concerns that the stored samples could be used by the firms for other studies without the knowledge and consent of the donor. It is not difficult to imagine the value of such data to insurance companies who could ameliorate potential losses by ever more targeted, premium, rates for people labelled as having a higher likelihood of developing certain conditions.

16.3 Surrendering bio-data is integrally bound up with the notion of informed consent to any intrusion into a person's privacy. In other words, *informed* consent is a social justice issue. The solidarity of Christ, expressed in the metaphor of 'surveillance from the Cross', demands justice, not mere equity of treatment where consent to bio-data gathering is dependent upon educational or economic advantage.

16.4 Similarly, surveillance that enhances the flourishing of people must take seriously the threat of re-identification of anonymised information.¹ 'People with leprosy' who feature in the Gospels can be a paradigm for all who are sorted and acted upon by the gathering of surveillance data. On the one hand, concerns for public health are valid, but as re-identifying of individuals within large datasets becomes more sophisticated the temptation to monetise this information increases considerably.

16.5 Whether by accident or malicious intent, data that can be processed to re-identify people with existing or likely future conditions endangers not merely their privacy but their status in society. Their visibility is taken out of their control. Jesus who surveilled from the Cross is the one who declared in his Nazareth Manifesto that he had been sent 'to proclaim release to the captives...and to let the oppressed go free' (Lk 4:18). Rigorous legislation does not immunise against temptation, so whilst Christians ought to advocate for the former we must be ready to be bearers of the Kingdom of God, that is evident in freeing those who are, or who will become, oppressed through re-identification of anonymised personal health information.

[See full report](#)

¹ Yves-Alexandre de Montjoye and others, 'Unique in the shopping mall: On the reidentifiability of credit card metadata,' *Science* 347: 6221 (2015), 536-39; Greg Slabodkin, "Data Re-Identification Remains Risk Despite HIPAA Safeguards", HealthData Management <http://www.healthdatamanagement.com/news/data-re-identification-remains-risk-despite-hipaa-safeguards> (accessed 30-Oct-2016); Russ B. Altman and others, 'Data Re-Identification: Societal Safeguards,' *Science* 339 (2013), 1032-33.