

## **Preface: Medical Confidentiality and Privacy: Past, Present and Future<sup>1</sup>**

This special edition of the *Journal of Medical Law and Ethics* arose out of a symposium held at the University of Glasgow on 25 and 26 April 2014, supported by a grant from the Wellcome Trust (Grant Number: 103499/Z/14/Z). Co-organised by the Centre for the History of Medicine at the University of Glasgow and the Centre for the History of Medicine and Disease at Durham University, the symposium was designed to bring together experts representing a range of research interests, practical experience and theoretical knowledge relevant to the theme 'Medical Confidentiality and Privacy: Past, Present and Future'. The positive response we received, from leading figures in a range of fields, resulted in a varied and engaging programme of presentations and discussions. We are delighted that many of those who presented papers at the symposium have developed their work into written contributions for this special edition.

In keeping with the original aims, the papers within this double issue of *JMLE* represent the perspectives of experts drawn from a number of academic disciplines and beyond. This includes specialists in medical law, medical education, clinical research, professional regulation and the history of medicine and health.

Fiona Flannery's paper notes that confidentiality and privacy are complex issues in medical practice, often requiring detailed consideration of the specific circumstances of a case and a measure of professional judgement by the doctor(s) involved. Unsurprisingly, each year the General Medical Council (GMC) receives numerous questions relating to these issues. The GMC is currently reviewing and revising its published guidance on *Confidentiality*, which was last updated in 2009. However, as Flannery notes, even in this relatively short timeframe, account must be taken of developments in law and emerging challenges in relation to integrated and shared electronic record systems, the rapid growth in use of mobile technology, tele-health and the secondary use of patient information within Big Data research.

Emma Cave questions whether aspects of the current GMC guidance on confidentiality have the potential to contravene patients' human rights, and may be contrary to legislative intent in the Mental Capacity Act. Her contribution specifically examines the evolution of the law and guidance with respect to patients who withhold consent to disclosure of personal medical information in situations where non-disclosure will cause them serious harm. Distinguishing between incapacity resulting from impairment of the mind or brain, and impairment of autonomy resulting from third party intervention (e.g. coercion or undue influence), Cave traces the development of a complex set of rules and tests to determine capacity. Ultimately, she argues for a revision to GMC guid-

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<sup>1</sup> DOI 10.7590/221354015X14319325749955

ance on the issue, to reflect recent developments in law and to enhance conceptual consistency.

Al Dowie notes that the GMC guidance on confidentiality plays a significant role in setting the UK agenda for educational approaches to teaching and training undergraduate medical students. Dowie's paper contrasts romanticised Victorian and Edwardian ideals of medical confidentiality and professional (gentlemanly) honour with the subsequent development of more detailed frameworks of clinical accountability through medical law, ethical codes and professional regulation and guidance. Recognising that students can readily engage with issues of medical confidentiality and privacy with little or no prior teaching, Dowie highlights a range of ways in which their understanding and knowledge of this core element of medical practice and identity can be developed and tested through elements within the taught and 'hidden' curriculum.

Michael Soljak's paper gives an account of the background to, and challenging development of, the care.data scheme in England. Vast amounts of data are generated through widespread use of the National Health Service (NHS). Noting that centralised systems have collected data from secondary care for decades, Soljak emphasises the potential benefits of primary care patient information also being drawn together centrally and made available for commissioning and research purposes. His paper recounts how recent attempts to implement the GP Extraction Service in England provoked a backlash from elements of the print media, patient advocacy groups, the House of Commons Health Committee and others, amid concerns over a range of issues, including a lack of public awareness of the scheme and suggestions that information in other datasets had been sold to insurance companies. Put on hold in early 2014, a revised version is scheduled to be piloted in a limited number of GP practices in 2015.

Jean McHale's contribution also includes an examination of care.data, using it as a case study of recent challenges to privacy and the confidentiality of personal information. More broadly, her paper argues that health care confidentiality stands at a critical turning point. Noting that confidentiality has never been an absolute obligation, McHale explores recent developments in the NHS's approach to confidentiality and privacy, before moving on to discussion of care.data. She concludes by suggesting that current engagement with these issues, at both European and national levels, presents a pivotal opportunity to frame and assert individual rights and obligations and competing disclosure considerations, with serious consequences if wrong choices are made – including fatal damage to patient confidence and trust.

Amy Fairchild's paper presents an account highlighting the various ways in which citizens have asserted their rights – to know, to be counted, to resist, as well as to have their privacy protected – in ways that have shaped the politics of public health surveillance in America since the 1970s. She explores the examples of public health monitoring of cancer cases, and the controversies regarding the notification of HIV/AIDS cases. Drawing out both similarities and differences in themes and approaches, Fairchild uses these case studies to illus-

trate that attitudes to confidentiality and privacy were far more varied and complex than any straightforward narrative of patients, citizens and their advocates, asserting a right to privacy against the searching eyes of public health authorities.

Andreas-Holger Maehle's article provides a comparison of the evolution of approaches to medical privilege in America, Germany and Britain. Drawing on a growing body of work on this topic, Maehle uses the development of statutes, case law and regulations to examine the development of different attitudes and approaches to doctors' disclosure of patient information during legal proceedings. Ranging from an outright rejection to various degrees of recognition of medical privilege within civil or criminal courts, local attitudes were influenced by a variety of factors. These included weighing the public health impacts of disclosing confidential information against the consequences, for justice, of excluding evidence from court. As Maehle notes, the treatment of confidentiality in court was also heavily influenced by power relations between the legal and medical professions within each country.

Angus Ferguson's contribution notes that while medical confidentiality is often given a pedigree traced back to classical antiquity, recent historical research has begun to provide more detailed accounts of how privacy and confidentiality have evolved over the course of the modern period. Such work brings new insights into the ways in which issues, individuals and interest groups have shaped developments, driven by pragmatic concerns as well as theoretical arguments. Ferguson emphasises that history has a number of important roles to play in contemporary debates over privacy and confidentiality. These include filling gaps in knowledge of the foundations of current practice; analysing and contextualising the evidence on which existing interpretations of law, regulations and policy are based; and promoting improved understanding of these complex issues across all stakeholders – patients, professionals, regulators, policymakers and the public.

A core aim, of both the original meeting and this special issue, is to illustrate the range of issues involving consideration of confidentiality and privacy, whilst encouraging interdisciplinary approaches and greater cross-disciplinary collaboration in future research. The breadth and complexity of these topics merits analyses that cross the boundaries between disciplines, and require both theoretical and practical input from within and beyond the academy. It is hoped that the articles presented here will provide a spur to encourage all stakeholders to engage with, support and promote such work going forward.

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