

# Why health services research needs bioethics

Lucy Frith

It is nearly 20 years since Tony Hope wrote an editorial in this journal on Empirical Medical Ethics,<sup>1</sup> arguing for both a recognition of the increasing amount of work being done in 'empirical ethics' and for its importance as a new direction for medical ethics research. Since then empirical ethics has flourished, with debates over the role of 'empirical' data in ethical reasoning producing a growing body of literature and the *JME* and other bioethics journals regularly publishing empirical studies. While bio/medical ethics has grappled with 'incorporating' or using more empirical data in ethical analysis, with varying degrees of success, and some criticism, there has not been a corresponding willingness of more empirical disciplines to embrace ethical analysis. This is a particular lack for applied research areas that see their role as predominately influencing policy and practice, such as health services research.

Health services research 'is the integration of epidemiological, sociological, economic, and other analytic sciences in the study of health services.' Whose 'main goals ... are to identify the most effective ways to organize, manage, finance, and deliver high quality care; reduce medical errors; and improve patient safety'.<sup>2</sup> Health services research brings together a wide variety of disciplines and would seem ideally placed to include ethics. However, if you search health services research journals and conference programmes there is very little consideration of ethics as a substantive topic and often scant attention paid to the ethical issues that might be raised by an intervention or policy. Ethics and ethical issues are generally confined to discussions over priority setting, and occasionally health technology assessment, with other areas of health service research seldom engaging in ethical debate. In the Encyclopaedia of Health Services Research,<sup>3</sup> ethics is addressed simply in terms of research ethics approval for studies. While ethical approval is clearly important—it is only one small part of what ethics can

contribute to wider health services research. Generally ethics has largely been ignored (with some notable exceptions such as the work of Trisha Greenhalgh and Mary Dixon-Woods).

There is a fear of making ethical judgements across health services research, with resistance to the inclusion of what is seen as subjective opinion that has no place in a body of knowledge that models itself on the natural sciences. Values are seen as personal and introduce a form of bias into discussions that should be about 'science' not opinion. As Weber put it, 'Whenever a person of science introduces his personal value judgement, a full understanding of the facts ceases'. Sayer<sup>4</sup> argues that this view, that any ethical assessment is merely unjustified subjective opinion, is apparent in attempts at a critical social science, where there has been reluctance to make ethical judgements due to an exaggerated fear of ethnocentrism or misjudgement. An example of this is, in an interview about her book *The Gene, the Clinic and the Family*, Professor Latimer expresses concerns that genetics could be used to refine humanity, by defining what is normal and discarding what is not. However, she says, 'In my book I resist making too many judgements'.<sup>5</sup> Further, although it is clear that health services research *does* consider some things to be wrong, such as structural health inequalities (ie, lack of access to health services due to prejudice or poorer health outcomes for certain demographic groups) as Sayer<sup>4</sup> notes these critiques, 'rarely set out their normative standpoints, their conceptions of the good, from which they launch their critiques'. He goes on to argue 'that critique cannot avoid such standpoints, though it may hide or fail to notice them; we need to make them explicit'.

So why is there a reticence to engage in ethical debate in health services research? It is beyond the scope of this brief piece to develop a 'sociology of health services research', although that would be a useful project, but a few key features can be sketched here, which are relevant across countries. First, the rise of evidence-based medicine has led to an increasing focus on aggregated and statistically derived data<sup>6</sup> and the desire for generalisability to make findings appealing to policymakers.<sup>7</sup>

Second, the perceived 'crises' facing healthcare funding and the problems of increasing demand (an ageing population; increasing technological developments; rise of chronic disease, etc) have led to calls for more efficiency and efficacy and to, what some authors see as, the dominance of micro-economic thinking.<sup>8</sup> Third, the rise of 'audit culture'<sup>9</sup> and the corresponding need for measurable metrics to demonstrate outcomes.<sup>10</sup> These elements can be broadly termed a form of scientism<sup>11</sup> that permeates health services research and seeks to produce objective knowledge that can be generally applied. While it could be argued that we are moving away from a crude form of scientism, with a greater acceptance of qualitative research and recognition of the importance of public involvement in the research process, there is still a hierarchy of research evidence with the randomised-control trial as the gold standard. In the unit of assessment in the last research excellence framework in the UK (UoA 2), for example, that covered health services research, there was a perception that small qualitative studies and ethical debates (thought-pieces) would not be as well ranked as studies employing quantitative methods.

The difficulties with studying health services using methods that seek to mimic the natural sciences have been well rehearsed,<sup>12</sup> attempting to emulate the natural sciences is problematic for research areas that deal with people in their social environments. When considering social science, for example, Flyvbjerg<sup>12</sup> argues that it has a different role from the natural sciences and he proposes a 'phronetic' social science that incorporates practical reasoning (phronesis), power relations and active engagement. Other critiques, such as Sayer's,<sup>4</sup> argue that social science needs to consider the ethical aspects of human experience, 'lay normativities'. These arguments can be just as well applied to health services research.

As noted, the 'empirical turn' in bioethics has radically changed the discipline, and I argue that it is now time for this debate to be turned on its head. Disciplines such as health services research need to explore how to address and theorise the ethical aspects of policy and practice. We need a 'normative turn' in health services research that encourages the development of 'an ethical, rather than sociological, imagination'. Work needs to be done on how this might be theorised. Flyvbjerg and Sayer's accounts, at their root, seek to break down the fact value distinction and theorise a more

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dynamic relationship between the two: value-rationality for Flyvbjerg and, for Sayer, the rationality of ethical judgements (that these judgements are based on reasons that have a relationship to external factors). This is one way to go, there are of course others, and many ethicists will want to keep the fact/value distinction (however construed). However, we need to begin the theoretical debate over how health services research can develop its 'ethical imagination' and what forms this could take is an area ripe for exploration.

Ultimately, value judgements have to be made, such as do we focus on prevention and public health or acute secondary provision? Such judgements are a crucial part of service design, treatment regimens and health policy. However, these judgements are often rendered invisible, subsumed under a technocratic discourse that reduces everything to effectiveness, efficiency and efficacy (eg, the use of quality adjusted life years (QALYS)). As Kelly *et al*<sup>13</sup> note, 'preferences for efficiency and value for money are value preferences, not scientifically neutral and dispassionately observed matters of fact'. In making these judgements we need to subject them to scrutiny,<sup>14</sup> to be open and to recognise that we can have a reasoned debate about ethics, as the work of many bioethicists and this journal testified to! Including ethics as one

of the key disciplines within health services research and incorporating ethical analysis alongside a consideration of the social, psychological, economic, clinical and logistical aspects of service delivery will, I believe, ultimately, enhance patient care. This is a plea for an augmentation of health services research, an addition, not a replacement of the existing central disciplines and methodologies. Ethics, I believe, can sit alongside the other disciplines that make up this area of research. It can contribute to a greater understanding of healthcare and give guidance and insight into the appropriate goals of policy and practice. Most importantly, bioethics has the tools to advance a critical perspective on modern healthcare—and this is a resource that should be embraced not marginalised.

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