



People-Powered Medicine

A one day symposium investigating public participation in medicine and healthcare from the nineteenth century to today.

The Carer as a Critical Friend

Ruth Richardson (King's College London)

This talk examines a nineteenth-century case in which a young patient's father recorded and compared the care regime in two hospitals. The record focused on a number of concerns including nursing, under-staffing, hygiene, security, appropriate treatment, secrecy, pain-relief, equipment and medication. It offers a fascinating view of hospital facilities and care before Nightingale and Lister, and illuminates the manner in which different medical charities and the medical men belonging to them worked at the time. The talk concludes with a look at the important role of the critical friend, and considers the beneficial long-term impact of this case.

“Don't you think the Moorfields doctors knew better than this Indian?” Victorian eye surgery, patient choice and the 1893 trial of the Indian oculists

Kristin Hussey (Queen Mary University of London)

In the autumn of 1893, the trial of a group of Indian eye doctors, or oculists, at the Old Bailey captured the attention of the British medical community at home and abroad, as well as the interest of the general public. Reported in over 20 British newspapers, the case followed four itinerant Muslim oculists from the Punjab region who had for the past months been couching for cataracts and claiming to cure eye diseases in the West London suburbs. From the baying crowds, which greeted them at the courthouse, the expert medical witnesses from the metropolis' leading ophthalmic hospitals, and the working class people whose testimony formed the basis of the case, the Indian oculists' trial provides a fascinating insight into the increasing importance of ocular health. Crucially, the transcripts of the trial reveal the power of the working-class patient in selecting their own preferred group of practitioners, as well as the extensive colonial networks which converged in London. Mixing professionalised medicine, Anglo-Indian surgical experience, and the continued appeal of quack medicine, this paper will use the example of ophthalmology, and the 1893 trial in particular, to consider London's thriving medical marketplace in an age of specialisation.

Patient Resistance in the Early Twentieth Century

Claire Brock (University of Leicester)

This paper will consider the ways in which patients who sought hospital treatment also fought their practitioners over that care. I will focus on the rich archive of case notes from the Royal Free Hospital, concentrating on those women treated by female surgeons in the Gynaecological Department between 1902 and 1919. When women began to enter the medical profession in the second half of the nineteenth century,

they campaigned for the right to treat their own sex. They argued that this was what female patients desired, especially when shameful and embarrassing gynaecological conditions meant that women often did not seek male medical advice at all, until it was too late. Similarly, early twentieth-century gynaecological surgeons castigated the largely working-class female hospital patient as passive and resigned in the face even of crippling malignant disease. Historians of medicine have followed suit. However, in reality, the relationship between female patients and practitioners was more fraught. Even when treated by their own sex, women were active participants in their institutional visits. I will explore how and why they struggled, through an investigation into the resistance only too apparent in patient records.

Building Communities, Changing Practice

Roberta Bivins (University of Warwick)

Using the examples of the genetic blood disorders sickle cell anaemia and thalassaemia, I will explore the ways in which patients, their families and their communities became key actors in medical research in the NHS. UK genetic researchers were swift to recognise that the arrival of new migrant communities in the 1950s and 1960s also brought new opportunities for cutting edge research. Initially, they may have envisioned their patients more as research substrates than as collaborators. However, by the 1970s, community members themselves began to leverage their political, as well as their biological distinctiveness, to reshape research agendas and priorities in the provision of NHS services. I will briefly ask what helped to empower such cooperation between patients and researchers and what limited the development and expansion of the 'unimagined communities'.

Patient-Consumers? Patient Organisations and Health Consumerism in Post-war Britain

Alex Mold (London School of Hygiene and Tropical Medicine)

Over the last fifty years, British patients have been made into consumers. Since the 1960s, concepts common within consumerism have found a place in health policy and practice. In a short space of time, the position of patients in Britain appears to have changed fundamentally. For instance, until relatively recently, it was not uncommon for patients to be told little about the condition that they were suffering from or its likely outcome. That such a situation would be (almost) inconceivable today points not only to changes in the doctor-patient relationship, but also to a wider shift in the way in which patients see themselves and are seen by others. This paper aims to explore how and why such a shift took place, and why it was that these changes were framed by the concept of consumerism.

Beginning in the 1960s, the activities of a number of voluntary organisations were central to the making of the patient into a consumer. Groups such as the Patients Association and the College of Health played a crucial role in the development of patient-consumerism. This can be seen in relation to seven key areas: patient autonomy, representation, complaint, rights, information, voice and choice. Such concepts were used initially by patient organisations to construct the figure of the patient-consumer, but by the 1990s the government had taken over as the main actor shaping ideas about patient consumerism. This development raises wider questions not only about the nature of patient consumerism, but also about the role of voluntary organisations in contemporary health policy and practice.

Bringing anatomy out of the shadows

Tom Gillingwater (University of Edinburgh)

“Our bodies are our gardens, to the which our wills are gardeners” (Act I of Othello; William Shakespeare). Anatomy, the study of the physical structure of the body, remains core to our understanding of what and who we are. And yet, for the last 100 years or so, levels of anatomical knowledge and awareness amongst the general public have remained low, largely due to anatomy education being restricted to those receiving medical training. Professional anatomists have long recognised the need to open up anatomy departments and teaching to a broader range of visitors who would benefit personally and/or professionally from a greater understanding of human anatomy. In my talk I will detail our experience of launching a successful series of public anatomy workshops at the University of Edinburgh, with the aim of widening access to anatomy education across a broad spectrum of society.

From body-parts to curriculum-setters: the changing role of the patient

Rosamund Snow (University of Oxford/The BMJ)

Medical journals have always featured patients, but traditionally the reader has only been able to see these patients through medical eyes. Journal conventions have changed over time, moving from descriptions of the moral and aesthetic virtues of the Victorian patient through to more modern references to disembodied body parts and blood test results. However, the patient’s doctor has always decided what counts as relevant information to share with peers about a person or a disease. Rosamund Snow, the *BMJ*’s Patient Editor, argues that this is changing, and describes the radical shift taking place in medical education and publishing that is already redefining the way doctors learn.

Symbolic acts, strategic gains: patient and public involvement in the English NHS

Christopher McKeivitt (King’s College London)

Globally, patients are being reconfigured as active collaborators in the production and maintenance of their own health, in quality improvement in health care delivery, and in the production of new medical knowledge. In England, patient and public involvement in NHS service development is legally required; involvement in much medical research is by now a de facto requirement. In contrast to self-organised health activity (embodied health movements, or biosocial citizenship) patient and public involvement is state authorised and directed. But how is this enacted and to what effects? Using examples from efforts to involve stroke survivors in research and NHS service development, this paper argues that involvement practices constitute a form of symbolic representation. Through ritualised action and discourse, these assert new ‘truths’ about the relationship between state and citizens, and between categories of citizen. Involvement practices yield diverse gains for state, professionals, and patients.

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‘Constructing Scientific Communities: Citizen Science in the 19th and 21st Centuries’ is an AHRC funded project based at the Universities of Oxford and Leicester which brings together historical and literary research on the nineteenth century with contemporary science. It looks at the ways in which past patterns of popular communication and engagement might offer ideas and models for scientific and medical practice today.

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