
Should patients tell researchers what to do? If so, how?

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RESEARCHERS SHOULD IGNORE PATIENTS



BIOGRAPHY

I have been employed in my current position as Senior Lecturer and Consultant Gastroenterologist at Newcastle since 1999 and work in clinical gastroenterology, research and teaching, roughly evenly divided.

My research interests have always been cosmopolitan, in contrast to the current fashion to pursue single diseases and themes. Having started from simple clinical observation, I did an MD on the relationship between meat intake and colorectal cancer and have continued to work on diet and gastrointestinal disorders. Currently my main research area is medical education and in particular the changes brought about by Modernising Medical Careers, but I am also interested in the role of Medical Humanities in medical education and have led a project examining the effect of a photographic elective on students' learning.

The views of patients have always been important to me and after some fairly quick and dirty research of patients' views in ulcerative colitis, I collaborated with others to undertake a 3 year investigation of professional-led self management in patients with ulcerative colitis, funded by the National Lottery. Further work on the research priorities of people with ulcerative colitis led to my sole publication in this area. Subsequently we have investigated the views of researchers and performed a Q-sort study of the views of the two communities.

I believe that we need to democratize research but that that process need not, and must not, weaken excellence.

ABSTRACT

The premise of my contribution is that the proposal would sound absurd if it was reversed: 'Researchers should totally ignore the views of patients.' This talk will, then, examine:

- Current research themes and priorities
- Motivations behind research
- How patients' views might be incorporated
- Barriers and drivers to this occurring

I will briefly outline the basic themes examined by research and raise the question of whether these are all adequately represented by current research funding using national funding data.

Incorporating patients' views of research priorities takes place against a backdrop of many other drivers of research:

- The interests, training and skills of researchers
- The need to get funding and so the views of funding bodies whether government or charity-backed or industry led
- The effects of the Research Assessment Exercise on University funding
- The need to publish and the ease of getting published and the relevance of impact factors
- Timescales for research
- The media

- The general public view e.g. breast cancer versus alcoholic liver disease or mental health

If the premise of the talk is accepted, the question then becomes not whether researchers should listen to patients, but a related series of questions:

'Which patients should we listen to?'

'How should the views of all patients be incorporated?'

'How should the differing views of patients be sifted and prioritized?'

'How do we ensure that the views of a vocal and well-organised minority (or even a majority) do not over-ride the views of a minority?'

'How much attention should be paid to the views of patients?'

'What are the barriers to success?'

'What are the drivers for success?'

The talk will conclude with a discussion of different models by which patients' views might be captured and incorporated and look at some of the evidence for the effectiveness of the models.

To summarize, there are a number of factors that maintain the current status quo and provide barriers for the greater democratization of research but some drivers that could promote greater involvement. We are just at the beginning of knowing how to incorporate the research priorities of patients and much more evidence of effectiveness is needed.

RELEVANT COMPETING INTERESTS

None

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