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

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#### **SIMON DENEGRI**

STORMY WATERS OR JUST UNCHARTED?



#### **BIOGRAPHY**

Simon Denegri joined the Association of Medical Charities (AMRC) as its Chief Executive in February 2006. Previously, Simon had been Director of Corporate Communications at the Royal College of Physicians of London from 2003. He was Assistant Chief Executive at the Alzheimer's Society (UK) from 2002 to 2003 and its Head of Public Affairs from 1992 until 1997. In the intervening period he was Corporate and Financial PR Manager at Procter & Gamble in the United States and then Director of Communications at the Sainsbury Centre for Mental Health (SCMH). He has written and spoken extensively on issues concerning health and healthcare policy and practice.

#### **ABSTRACT**

Improving civic engagement in society is a challenge facing policy-makers across government, and health and medical research is no different. Such research is fundamental to ongoing improvements in health and well-being - a key marker of a modern society. Yet the way it is currently designed and managed does not always reflect the way that society is changing around it. Not least the many opportunities that might accrue through enabling greater participation and involvement by patients and the public.

Ensuring access and providing opportunities to people to become involved will require a culture change in research. Not everyone will grasp that opportunity. But for others 'research citizenship' will be as important as casting their vote in an election.

This presentation will examine the current seascape that is patient and public involvement and where it might land. The waters in between are certainly uncharted but need not be stormy. And they are certainly worth navigating if science is to avoid being cast adrift in the doldrums by those who it needs and need it most - patients and the public.

#### **RELEVANT COMPETING INTERESTS**

Grants/Research Support: None

Consultant or Advisor: Member, UK Clinical Research Collaboration (UKCRC) Patient and Public Involvement (PPI) Working Group and Chair, UKCRC PPI Strategic Review (ongoing)

Member, INVOLVE Working Group on Strategic Partnerships

Company financial interest: None

Other: None

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