



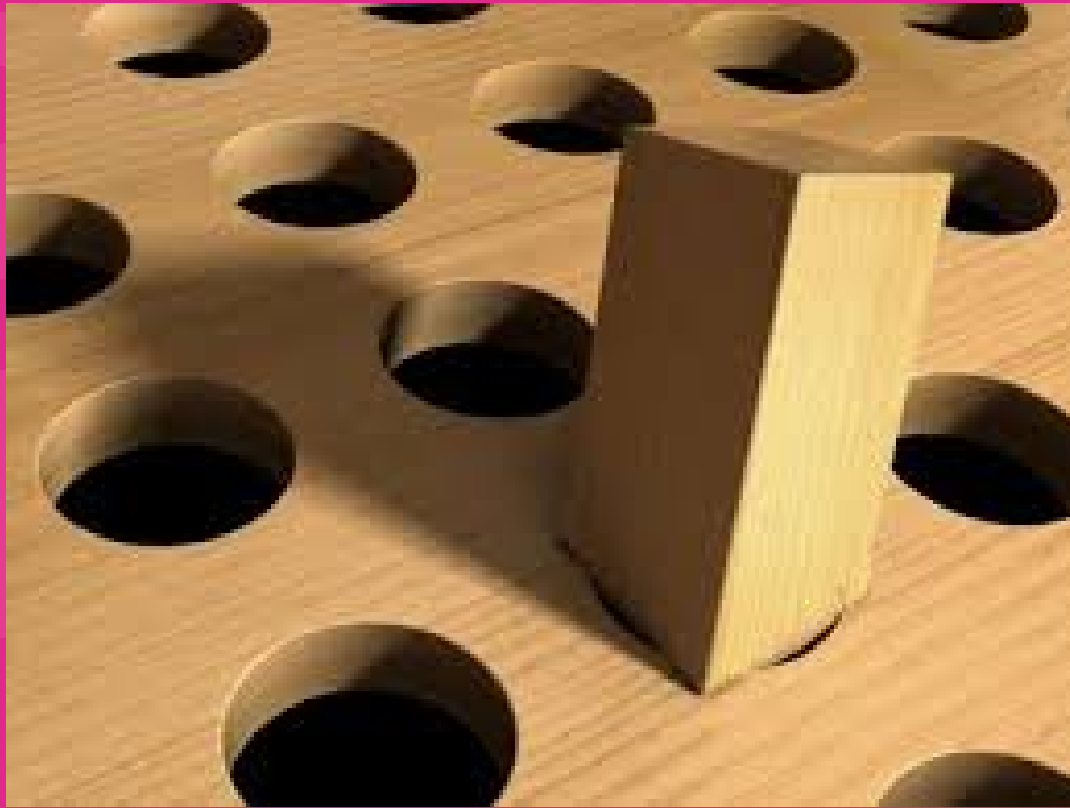
# Patients – The Missing Link?

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VP Program Investment,  
Alberta Cancer Foundation

May 20, 2015



**Alberta Cancer**  
FOUNDATION



**“Who should ultimately design the product?  
The customer, of course.”**



*Source: Philip Kotler*

# Adding Value

*'Only 9% of patients wanted more research on drugs yet over 80% of randomised controlled trials in patients with osteoarthritis of the knee were drug evaluations.'*

*'Relations between the agendas of the research community and the research consumer' Talon et al, Lancet 2000 as cited by Iain Chalmers and Paul Glasziou, The Lancet 2009*

Picker Institute Europe

www.picker-europe.org

Apps Alberta Cancer Found... AIG Webmail (Remote) Home - AIG Insite Gmail Email from Google Alberta Cancer Found... OneView Internet Login Dropbox - Sign in - Sim... Home Welcome to the... Citrix WebApp - Logon Imported From IE

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A changing government but the focus needs to remain on person centred care

Where does the newly elected Conservative government need to focus to tackle high quality care delivery for all

Patient Experience Network Part 2 – organisational highlights so far and the future

RT @BeVirtuallyCafe: Thank you so lovely ReTweeters @PickerEurope @MauCounseling @SgtChaps @robeynit : Spreading the word on mentalhealth @MH1W2015

Election 2015: The patient experience challenge

Data collection begins on real-time feedback collaboration, with University of Oxford

Top stories Research & Policy Our work in practice

Working with you to **improve the quality** of health and social **care**.

Picker Institute Europe is a leading international charity in the field of person centred care. We have a rich history of supporting those working across health and social care systems to use people's experiences to improve care quality.

www.picker-europe.org





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## What is INVOLVE?

### What we aspire to:

A dynamic partnership between the public, researchers and others, to advance NHS, public health and social care research and improve the health and well being of the population

Established in 1996 INVOLVE is a national advisory group funded by, and part of, the National Institute for Health Research. <http://www.invo.org.uk/>

### How we do it?

- Leadership across NIHR
- Build and share the evidence base
- Develop capacity and capability
- Influence policy and practice



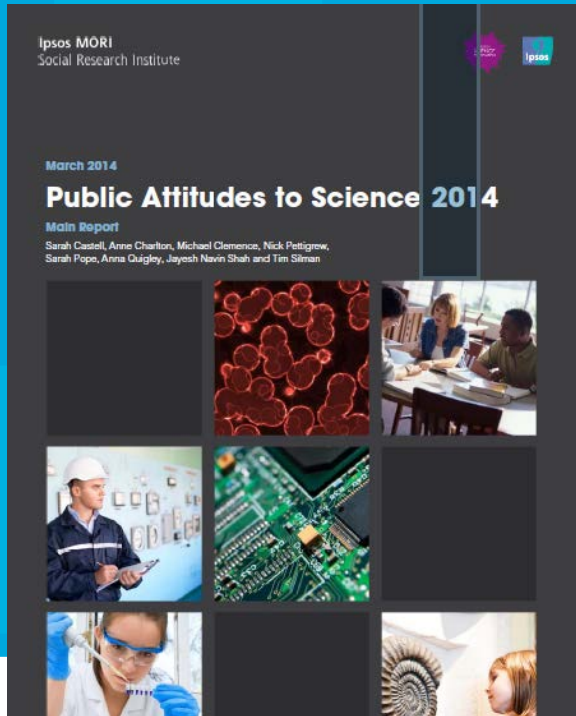
# Increasing Research Effectiveness and Efficiency

*'The aim of patient and public involvement is to improve the quality, feasibility and translational value of research... [This] is the first time we can see that patient involvement is linked to higher likelihood of reaching recruitment target – and as a result, study success.'*

Professor Til Wykes, Director, MHRN  
'Patient involvement in research boosts success,'  
The Guardian, 16/09/13

**Paper reference:** Ennis, L. et al. 'Impact of patient involvement in mental health research: longitudinal study' *British Journal of Psychiatry* (Sept 2013) [doi: 10.1192/bjp.bp.112.119818](https://doi.org/10.1192/bjp.bp.112.119818)

# But what about the patients?

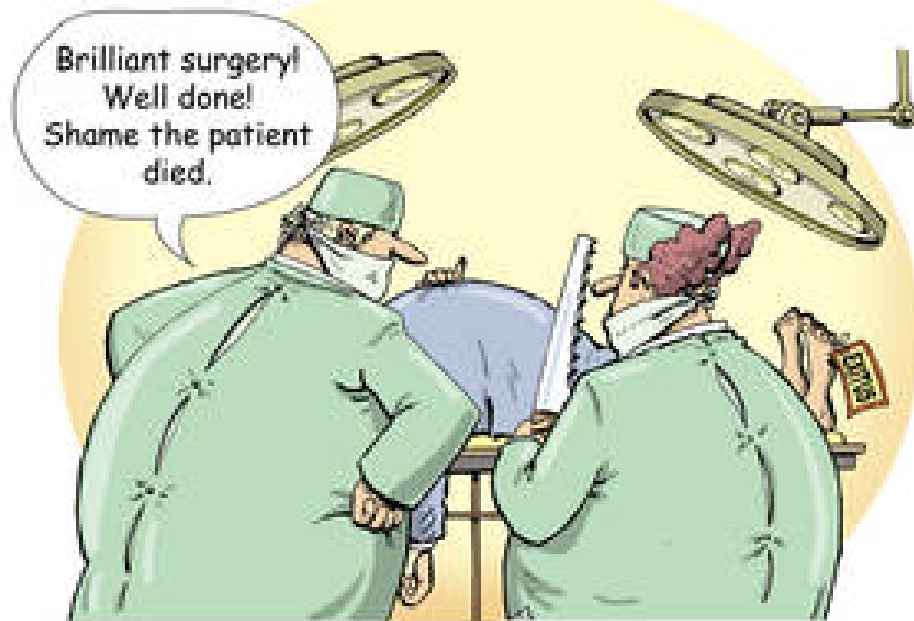


- 7 in 10 people think that Government, regulators and research organisations should listen to the public more

- 3 in 10 of us would be willing to get involved

*PAS Report, 2014, Department for Business, Innovation and Skills* <https://www.ipsos-mori.com/researchpublications/researcharchive/3357/Public-Attitudes-to-Science-2014.aspx>

# Do outcomes matter?



*'If this living forget it, doc yes I know  
it is working but I cannot take this  
anymore.'*

Phase I Clinical Trial Participant

# Patients have a part to play

*'Subjective toxicities are at high risk of under-reporting by physicians, even when prospectively collected within randomized trials. This strongly supports the incorporation of patient-reported outcomes into toxicity reporting in clinical trials'*

J Clin Onc 33 2015 Massimo Di Maio et al

