How patient involvement has moved on in Cochrane

Amanda Roberts

“No matter how complicated the research, or how brilliant the researcher, patients and the public always offer unique, invaluable insights. Their advice when designing, implementing and evaluating research invariably makes studies more effective, more credible and often more cost effective”

Professor Dame Sally Davies, Chief Medical Officer for England

Brilliant blueprint

Simple

Challenge is to fully understand what you want from consumers and what they need, to achieve your future challenges – sustainability, speed of production, good evidence, tailored outputs, go to source

1993 (20yrs!) Cochrane Collaboration started

1997 Cochrane skin group started

Initially the only opportunity for patients to contribute was as a Lay summary referee

Now they can be the Lead or co-applicant/co-author; member or referee of protocols/lay summaries

What is in a name?

Consumer vs user, patient, lay, public., PPI

It matters as defines whole relationship.

Regardless we are talking about: lived experience of a condition (patient/carer), healthcare user or a non clinical/research perspective

One size does not fit all especially in dermatology

Age, ethnicity, lifestyle, geography and comorbidities matter

Your challenge to be sustainable needs to take this into account

Ever thought what motivates your consumers – maybe addressing these factors would help your sustainability. Could be giving back, championing, learning more about condition, wanting to do something (anything), fascination with research

Your production needs to be timely. Consumers need help in unlocking potential. Research terms; access to major health research engines; condition hindrance. Worth it. Sally Davies “*No matter how complicated the research, patients & the public always offer unique, invaluable insights*”

Cochrane has a reputation – it needs to continue to produce work based on good evidence. Most appropriate consumer (teenager for acne, French speaking for a French review?)

Doctor patient relationship brings whole lot of (unhelpful) baggage sometimes

Tailor outputs to end user – one size does not fit all. Lay summaries – (beginning) and award in 2012. Opportunity to do something specifically for patients in their own language? Is it easy for consumers to find the most appropriate information?

Go to source of information

Wouldn’t it be great if more end users knew about your resources? It would help in pull through of results

The truth is out there

Don’t forget – the reason you are looking for the truth is for the benefit of patients and you can’t do it without us. Now hand you over to the wonderful Maxine