


Engaging with patients and partnership working



A pragmatic model of priority setting – ‘all the P’s’

- ❖ **Product**
 - ❖ **Process (information)**
 - ❖ **Protocol**
 - ❖ **People**
 - ❖ **Partnership – CASE STUDY 4**
 - ❖ **Power**
 - ❖ **Politics**
 - ❖ **Pragmatism!**
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People

- ▶ They could be practitioner, policy maker, press, private sector, public and patients *
- ▶ What perspectives are you after – distinct experiences of a health condition or disease process or wider view of a health condition?
- ▶ First hand or proxy?
- ▶ ‘Sense check’ on your activities?
- ▶ Active decision maker?
- ▶ Active challenger?
- ▶ Creative thinkers? Patients often see the problem from different perspectives and think in different ways..... they bring their world into our world....

* Tugwell et al ‘Systematic Reviews and Knowledge Translation, WHO Bulletin, August 2006

Specifically.....

- ▶ Patients and their carers often know:
 - about living with a chronic disease or condition and living with multiple conditions
 - about more short term experiences of health care/services
 - about the impact of side-effects and adverse effects
 - about availability and appropriateness
 - of services
 - about what could make intervention *more* acceptable or *less* acceptable
 - what questions they want addressed for patient benefit
 - what their health problems are, and are motivated to find solutions

Arnsteins' ladder of participation


- ▶ Focuses on the levels of participation, from passive to active and the shift of power accordingly



- ▶ Partnering
- ▶ Engaging
- ▶ Consulting
- ▶ Informing

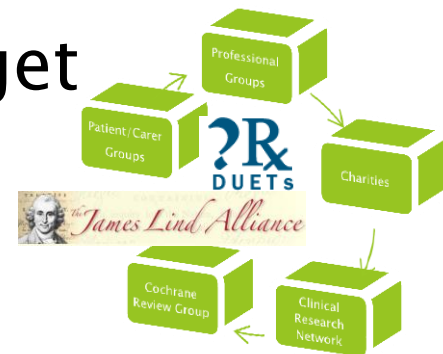
CASE STUDY 4

A Priority Setting Partnership in MS

- ▶ People
 - ▶ Partnership
 - ▶ Power relationships
 - ▶ Politics
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Partnership People

- ▶ People living with MS and carers and family members (MS Charities)
- ▶ Professionals that treat and care for people with MS (Professional organisations and therapy centres), some research active, some not
- ▶ Researchers
- ▶ James Lind Alliance (honest broker)
- ▶ UK DUETs (where the uncertainties get published)



PSP ladder of participation



- ▶ Co applicants in new research proposals
- ▶ Steering Group member
- ▶ Involvement in prioritisation workshop
- ▶ Voting for priorities
- ▶ Suggesting treatment uncertainties (survey, discussion, workshop etc)

Partnership Power

- ▶ “It’s usually people of prestige and affluence who advise people of influence”

▶ John Bell – Thought for the day – BBC Radio 4 18/03/13

- ▶ Careful constitution of the partnership and recruitment of partners
- ▶ All decisions made by the Steering Group, and sub groups – no behind the scenes stuff!
- ▶ Publically available minutes and actions
- ▶ Good chairing of meetings ensuring maximum participation, and ‘shared air’
- ▶ Seating.....

An example of working with data in a power sharing way...

- ✓ Original survey = 1084 uncertainties
- ✓ Formatted to ICPO standard by info specialist with support from Steering Group (SG)
- ✓ Classified according to the Health Research Classification Scheme as above
- ✓ Respondent data added, who suggested what?
- ✓ Similar questions grouped as above (971 in scope questions into 93 groups)
- ✓ Check these with SG and create and agree indicative questions for each group

Partnership Politics

How to manage the politics
in partnerships?

My rules are:

1. Don't ignore it
2. Really don't ignore it...

- ▶ Deal with the power issues, less likely for politics to derail your process
- ▶ Adopt transparency of process and dialogue
- ▶ Acknowledge that all partners have interests, self interests and bias – declare these
- ▶ Honesty broker role.....
- ▶ Someone having the mandate to take control if things go wobbly
- ▶ Not allowing the more powerful and influential to take control of the process, or the dialogue
- ▶ Ensuring that the excellent doesn't become the enemy of the good