Patient and Public Involvement (PPI) Feedback

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Background

- Palliative Care Studies Advisory Group established 2009
- Mixed lay panel of patients, carers, former carers
- Cancer, dementia, MND, COPD
- “Personal interest or experience in palliative care”

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- INVOLVE defines public involvement in research as research being carried out '**with**' or '**by**' members of the public rather than '**to**', '**about**' or '**for**' them.

See www.invo.org.uk for more.

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Discussion

- What are the priority areas related to this research?
- Any issues with the provision of financial support?
- Any thoughts on methods?

Priority areas - AGE

- Younger people may struggle more? Older people get free prescriptions etc.
- Disability benefits turned down for terminally ill step-daughter (cancer).

Ethnicity

- Less well supported
- Assumption that ethnic groups may be more family oriented, which can lead to support not being offered
- Public perception ethnic minority disadvantage has improved

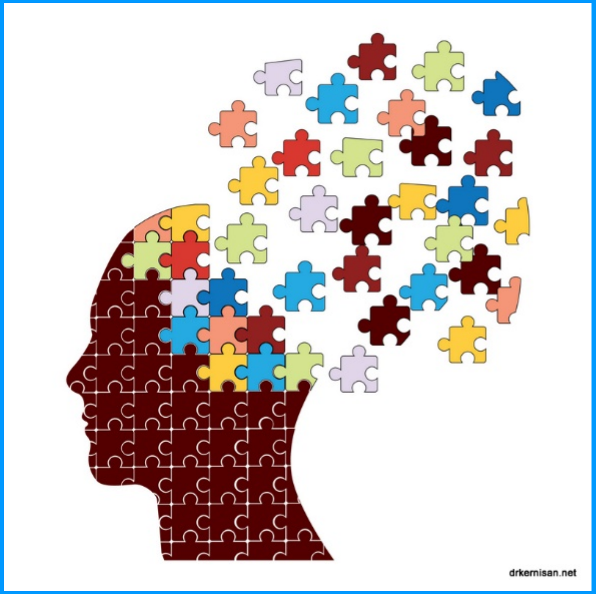
Education

- Financial burden difficult for those who are well-educated – very difficult for those less so

- *“There are many barriers …. you have to jump through so many hoops. These are barriers for everyone but for those from disadvantaged backgrounds it is virtually impossible to jump through those hoops.”*

Non-cancer

- Financial support is better resourced for those with cancer, also better support with managing costs
- “One area you should look at is dementia”
- Dementia support is very poor, long delays.



Caring and working

- Difficult to juggle employment with caring responsibilities

- *"I took early retirement to look after my wife [with dementia]"*

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Those without a carer

- Financial burden can be greater for patients where there is no carer.
- Patients with no carer may be especially vulnerable
- *"Benefit applications only got done because my husband did them".*

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Issues with provision of financial support

- Complexity of applications
    - *“There are many barriers – where there are resources available, the process to acquire those, let alone find out about them…. you have to jump through so many hoops”*

- Stigma
    - *“I just felt so humiliated – the impression he (consultant) gave was “I’m a really busy person and to have to do this…””*

Issues with provision of financial support

- Where to turn for help?
  - Who is in a position to make it happen? Who can help? provide information about support
  - *“You enter a world you know nothing about”*

- Government Funding
  - Perception that government support is reducing or *“sinking”*

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Summary

- Various groups of people ‘at risk’ or more vulnerable
- Important area of research
- Challenged assumption that this area of research is too sensitive/burdensome