



What are patients' priorities for research in Parkinson's Disease?

Research using a nominal group technique

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Introduction

- This research study will begin recruiting over the next few weeks and months
- The aim is to determine the views and priorities of groups that have an interest in Parkinson's disease research
 - Patients
 - Family members
 - Health professionals
- We aim to see if these priorities differ between the groups, and if so, why?



✦ Patient involvement

- Increasingly recognised as important
 - Research Governance Framework 2005
 - INVOLVE
 - Multiple DOH documents
 - MRC and Cochrane have patient groups
 - Considered an essential part of good research practice

✦ Why are patients' priorities important?

- Research priorities are often decided by professionals and funding bodies
- Priorities identified by patients often differ
- Important areas for research may be underfunded or ignored because they are not identified as important

Research priorities:

“need to respond to the professionals’ agenda but they also need to be congruent with priorities for healthcare research in general, which, in turn, must respond to the needs of healthcare systems and the populations served”.

From Tierney A. J. Nursing Research in Europe. *Int Nurs Rev* 1998; **45**(1): 15-18.

Areas of involvement

- Priorities
- Design of research
- Conduct of research
- Analysis
- Dissemination

🔥 What about this study?

- The chief investigator for this project has Parkinson's disease
- Involvement from the Parkinson's Disease Society Research Network
- Input from Parkinson's Disease Clinical Studies Group
- Plan to feedback results to participants and disseminate findings widely

🔥 Is it obvious what the priorities should be?



👉 Osteoarthritis priorities

Available research

- Drugs
- Surgery
-
-
- Education
- Complementary therapy

Rheumatologists

- Outcome measures
- Indications for surgery
- Felt drugs were over researched

Patients

- Conservative measures
- Education
- Self help
-
- Drugs
- Surgery

From Tallon D, Chard J, Dieppe P. Relation between agendas of the research community and the research consumer. *Lancet* 2000; 355: 2037-2040.

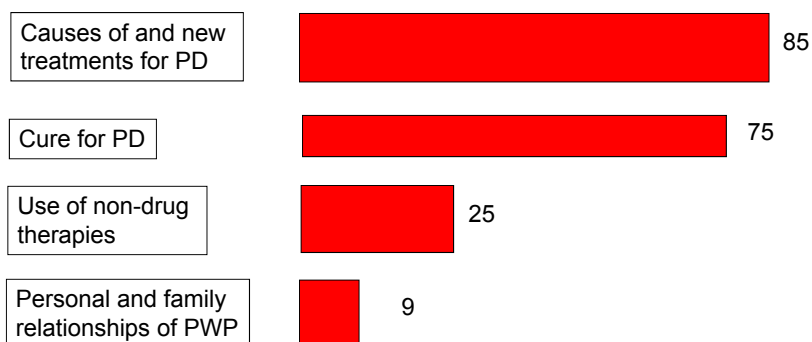
👉 Other research areas that have benefitted from patient involvement

- Osteoarthritis³
- Cancer care⁴
- Palliative care^{5,6}
- Diabetes⁷

☀️ Priorities for Parkinson's disease research: Previous work

- No formal scientific study
- Parkinson's Disease Society
 - Survey of members (most of whom have PD)
 - What types of research should the Society spend its money on?

☀️ PDS Members survey



Abridged version of data from the PDS members survey 2007. With kind permission from Kieran Breen, Director of Research and Development at the PDS.

✦ How best to identify research priorities



- Questionnaire?
- Focus group?
- Focus group then questionnaire?
- Nominal groups?

✦ Nominal groups

- Modified form of focus group
- Structured discussion with a group facilitator
- 6 to 8 participants

👉 Nominal groups



- Ideas generated by individuals

👉 Nominal groups



- Ideas discussed amongst the group
- Ideas rated and ranked by individuals and then the group
- Ideas amalgamated and clarified
- Aiming for a degree of consensus

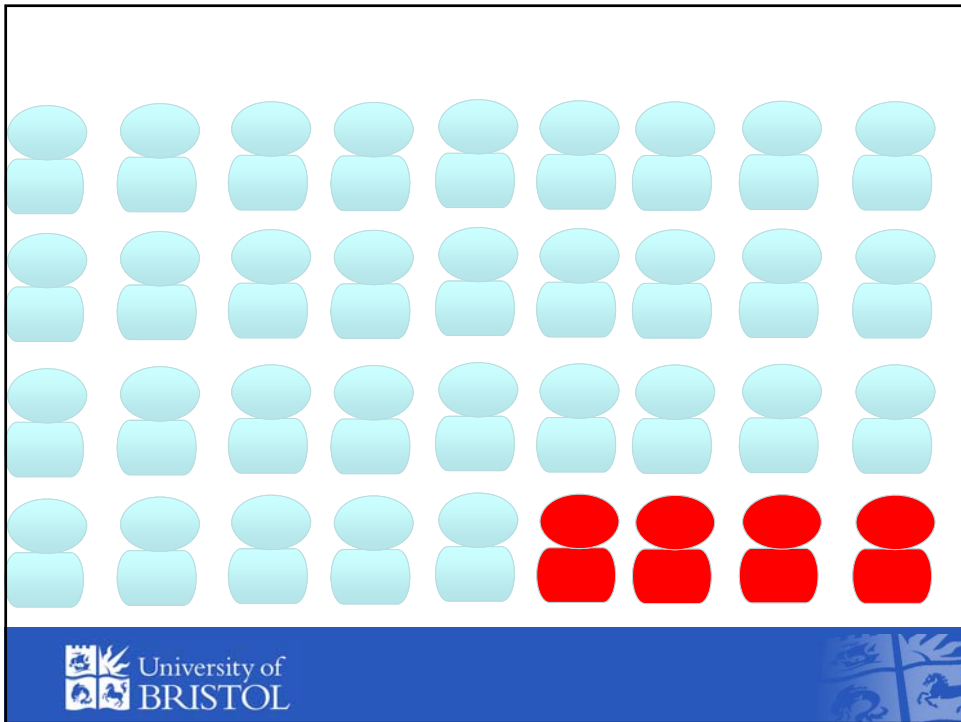
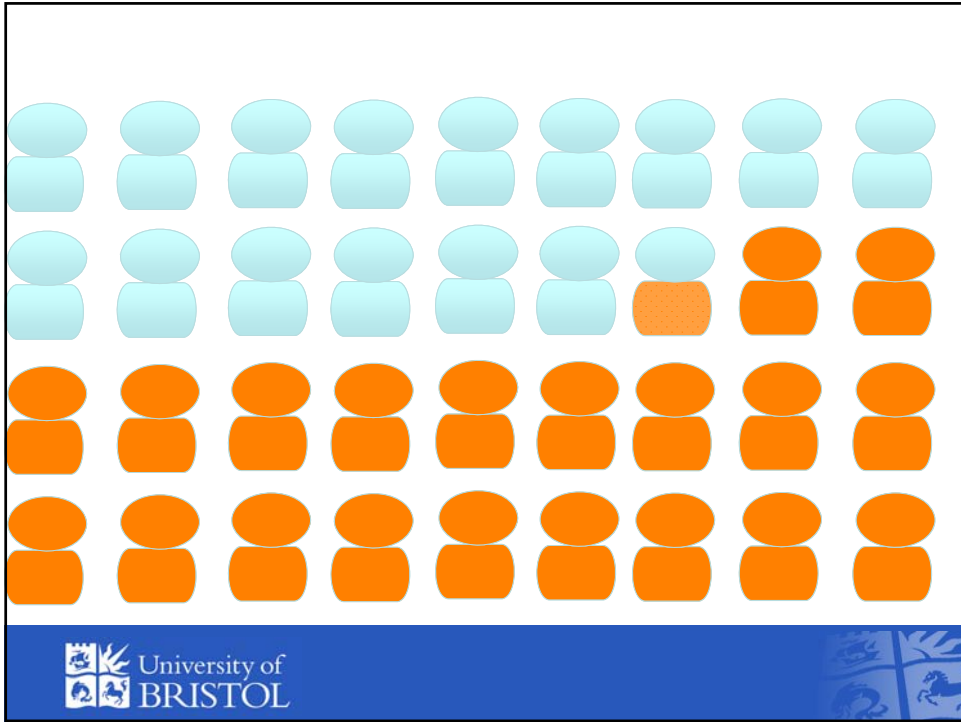
✦ Nominal groups



- Discussions are recorded
- Analysed for themes
- To give depth and power behind priorities

✦ Benefits of nominal groups

- Allow ideas to be generated by individuals
- Reduces the effect of dominant individuals
- Some protection from direct rejection
- Rating and ranking of ideas
- Detail and reasons behind priorities



Plan

- 11 nominal groups
- People with Parkinson's
 - Stratified according to the severity of PD
- Family members of those with PD
- Health Professionals involved with PD
- Members of the PDS research network
- Members of the PD Clinical Studies Group

Putting research into practice

- Dissemination to people with PD
- Dissemination to healthcare professionals
- Dissemination to funding bodies
- Follow up research
- Expanding involvement of people with PD in research

Further information

- INVOLVE
- Research Governance Framework
- Department of Health

References

- 1 Research Governance Framework. 2nd edition, London: Department of Health, 2005.
- 2 Tierney A. J. Nursing Research in Europe. *Int Nurs Rev* 1998; **45**(1): 15-18.
- 3 Tallon D, Chard J, Dieppe P. Relation between agendas of the research community and the research consumer. *Lancet* 2000; **355**: 2037-2040.
- 4 Corner J, Wright D, Hopkinson J, Gunaratnam Y, McDonald JW, Foster C. The research priorities of patients attending UK cancer treatment centres: findings from a modified nominal group study. *Br J Cancer* 2007; **96**(6): 875-81.
- 5 Perkins P, Barclay S, Booth S. What are patients' priorities for palliative care research? Focus group study. *Palliat Med* 2007; **21**:219-225.
- 6 Perkins P, Booth S, Vowler SL, Barclay S. What Are Patients' Priorities for Palliative Care Research? – a questionnaire study. *Palliat Med* 2008; **22**: 7-12.
- 7 Brown K, Dyas J, Chahal P, Khalil Y, Riaz P, Cummings-Jones J. Discovering the research priorities of people with diabetes in a multicultural community: a focus group study. *Br J Gen Pract* 2006; **56**: 206-213.