

## Some guidance on running DeNDRoN focus groups

Whenever any DeNDRoN committee faces complex issues, perhaps a problem which has come up, or a question about a particular study or area of research, then you might want to suggest that the committee sets up a focus group.

### If so, this guidance might help...

The aim is to discover the group's own ideas, views, priorities, or experiences:

- ✓ Participants may need briefing about the science
- ✓ Someone taking notes
- ✓ Select participants so as to create a positive environment
- ✓ Might be better to use individual interviews instead of groups
- ✓ Be clear about the specific purpose
- ✓ Guide discussion from the general to specific examples, and back
- ✓ Could have the key topics printed on large cards in the middle can help focus the discussion
- ✓ Start/end on time
- ✓ Payment is not usually appropriate
- ✓ Information on where participants can seek further support or information
- ✓ Ideally two moderators

#### **A focus group:**

- Is small (maybe 6-10)
- Focuses on a specific theme and topics for discussion
- Is interactive
- Uncovers a particular group's own views, priorities, fresh ideas, their own language and understanding, experience, opinions, BUT may need some briefing
- Has a minimum imposed structure
- Lasts up to 90 minutes
- Has someone taking notes

- Is more open-ended and explorative than a survey; sometimes a focus group might be used a stage towards to identify the key issues for a follow-up survey

### **The key challenges:**

- Be very clear about the purpose of a facilitated focus group meeting.
- Creating an environment allowing discussion of confidential and sometimes sensitive matters, without excessive individual-level data. (The subject matter may require a very small group or individual interviews instead.)
- Ensuring the moderators remain impartial and independent from the group

### **Selecting participants:**

- Clarify the objective first
- Clarify the target population
- Aim to have a diverse mix of participants who can produce robust outcomes. If everyone knows each other already, or comes from similar backgrounds, they will talk more freely. However, sometimes it is useful to mix different types of patients and/or carers – as they ask each other useful questions
- You might want participants to have pre-read a leaflet or document.

### **Group size**

- Larger groups are better for discussing a broader range of topics. They require more structure and directive steering
- Smaller groups allow more depth around a specific complex topic, but require participants who will be very engaged with the topic and are likely to be supportive

### **Designing the framework for focus group discussion:**

- Design an overall theme or framework with topics, not direct questions, structured so that they flow appropriately. The general flow might be successive stages in a process. Alternatively it might flow from the general/practical then on to the emotional/personal.
- No jargon
- A small initial pilot group can be helpful – or even just asking one or two individual patients to comment on your design in advance.

# Prompts for discussion at patient discussion groups about recruitment to research: these are examples of issues which can be raised during discussions

## “THOUGHTS AND WORRIES”

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### Doubts or cynicism about research in general

- Being a “guinea pig”
- Maybe ending up on placebo
- Poor level of care in the NHS fuels doubts about quality of research
- Results might not be put into practice
- Cynicism about NICE decisions

### Deciding whether to participate

- What might make it difficult to decide whether to participate?
- Not confident re benefits/side effects?
- Should the doctor/professional give advice? Whose advice seems most trustworthy? Do you think advice from medical charities affects decisions?
- Need to know all the possible unexpected results and implications (including long-term)?
- Is it right to want to identify cases EARLY and offer research in EARLY stages? Are there specific examples where earlier diagnoses could have been made, but no action taken?
- Awareness that there’s no dementia cure means benefit of participation in research needs to be explained
- Is the internet now used by a large proportion of patients and/or carers?

### Carer issues

- Are carers included properly, or left out of the loop when research is discussed?
- What information do carers specifically need about research?
- Issue of mental capacity and advanced directives w.r.t. carers
- Do carers talk to each other about research?

### Worries/fears

- Confidentiality – what are the specific issues here? Patients sometimes don’t want to take part in research if will be identified as dementia patient – Is there still stigma?
- Risk disappointment?
- Any specific fears? E.g. patient’s test results may uncover unwanted bad news?
- Should researchers be more certain about likelihood of future benefits to patients outweighing any risks to individual participants?
- Want to avoid being reminded about illness?

## **“PRACTICAL”**

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### **Finding out about research opportunities in the first place**

- No research taking place?
- Does there seem to be much going on, and where?
- Doctors/nurses don't seem to raise it?
- Is research mentioned when visiting dementia specialists?... by the Consultant, ... or by someone else?
- None around for certain particular stages of illness?
- Should GPs have financial incentives for being more involved with dementia patients?
- Are there any case registers you know of? Which places locally have a good or bad research culture and are there geographical variations? Do they talk to each other?

### **Practicalities around appointments and time issues**

- Geographical
- Travel issues
- Long/longer waits at research appointments? Research always adds more time to appointments than predicted
- Suggestion for special research parking places
- Particular issue about leaving people with dementia in cars whilst going to buy ticket
- Financial - Reimbursement can take a long time.
- Parking
- Work and family commitments
- Other time commitments

### **Health/independence**

- Living alone/No carer/family issues?
- Can't commit to attend as health unpredictable?
- Is it true that people can go from “not ill enough”, straight to “too ill”? e.g. exclusion criteria, or simply too ill to have the stamina to take part?

## **ADDITIONAL - TO ASK IF OR WHEN APPROPRIATE**

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- What can we do about variable strengths of research culture in different local cities? (can specify local towns or cities)
- What are the barriers around tissue transplant research?
- How do people feel about DeNDRoN covering neurodegenerative diseases as well as dementias?
- How can DeNDRoN involve local people (not just directly in studies)?
- What about any issues around advanced directives?
- How do you feel when you hear of exciting breakthroughs then hear nothing more?
- Do different types of the disease need different research approaches?
- Is it clear how the different research teams 'fit 'in' with each other?

# More about running the group

## Practicalities:

Clear and realistic planning of all the practicalities includes...

- timing,
- venue,
- room,
- budget, including childcare and transport, and any payments or incentives (if appropriate), refreshments, breaks,
- toilets,
- two full written frameworks (one for each moderator), with timings,
- participants' names register, and a demographic breakdown for reporting and meeting diversity governance requirements,
- all the necessary materials and visual aids,
- any specific props for the discussion (leaflets, pictures, prompt cards),
- information on where participants can seek further information

## Start the group:

- On time
- In a circle
- Welcome everyone and agree clearly what confidentiality means in the context
- Build a non-threatening atmosphere
- Ensure that someone is taking impartial notes for writing up afterwards
- The opening section should clearly signal that everyone is welcome and equally involved, and explain the rationale and purpose of the group
- Try to get everyone talking early using a round of introductions
- Something physical to handle or play with, or relevant pictures, can help break the ice and involve everyone
- No mobile phones
- Some participants may need to leave early – allow for this

## Two moderators:

Two moderators, ideally alternating for different sections, are better than one. The second moderator can take notes.

- It is not advisable to promise an answer to any specific questions, which individuals raise, unless you are confident that this is achievable. It is better to have referral details on hand

## The moderator:

- learns the framework by heart
- keeps strictly to time
- makes no reference to their own views

- uses simple, open-ended probing questions to seek clarification, depth, new angles, exploring contradictions
- encourages quieter people to talk by repeatedly asking for other people's opinions
- uses the minimum of reminders, key prompts and probes to keep the discussion around the framework topics
- avoids leading questions
- can have the key topics printed on large cards in the middle can help to ensure the discussion stays on the topics
- aims to guide discussion from the general to specific examples, and back to more general discussion, before moving on to the next section.

**End:**

- On time
- The fact that the group is about to end should be clearly signalled to participants
- The final section or topic should invite any further comments, and allow winding down time
- Thank the participants
- Explain again what will happen with the report of the group
- Explain how and when participants will be able to have feedback on outcomes, and specifically ask for permission to write to them or contact them in the future if wished

*Terry McGrath, PPI Coordinator, NIHR DeNDRoN CC - November 2008*