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Summary of DeNDRoN East Anglia patient and public involvement meeting on September 2008

Held in Thetford, on 4th September 2008 organised by the DeNDRoN East Anglia team.

There was a general introduction about DeNDRoN then the meeting split into two groups of patients, carers, ex-carers and DeNDRoN staff to discuss barriers to participation in research and how to overcome them. Research nurses Jenny Wilson and Niki Wyatt facilitated groups, with notes taken by Kim Clipsham and Juni West.

This report will help to inform thinking around these issues in DeNDRoN East Anglia.

The group mainly discussing the DOMINO study in dementia

The overriding clinical research priority for those present who discussed the DOMINO dementia study was quality of life. In terms of evaluating whether patients and carers would be interested in participating in the DOMINO study, the use of a placebo arm in the study was seen as a major negative potential impact on quality of life, and was considered very important. There was a question as to whether, even at this stage in the study, the researchers might be able to remove the placebo arm. It was, however, recognised that the funders (including the Alzheimer's Society) had supported including a placebo arm.

Another issue specifically related to DOMINO were that tiredness and time pressures for carers need to be considered when explaining the need for five visits in the first year of the study.

There was an expectation that patients and carers should be informed of research (such as DOMINO), without having to seek out information on research opportunities. It was felt by many present that they would prefer information to come via community nurses rather than doctors, and that support groups should have more of a role in promoting research. In view of the complex nature of the study, it was suggested that a source of "independent" advice on DOMINO could be useful.

- Note: In the other group discussion, there was wariness about being approached about research by anyone other than a consultant or nurse.

Additional staff comments:

- Loneliness of carers was highlighted as a problem. Perhaps therefore ensuring that the DOMINO research visits were a positive experience, might lead to more interest and a lower dropout rate, as carers share experiences via support groups.
- It proved difficult to balance a general discussion of research issues with focusing on DOMINO specifically.

The group discussing general issues around clinical research, with an emphasis on PD studies

In general terms, there was cynicism around the secrecy of drug companies, and also a broader concern that patients and carers should be informed of outcomes and future progress of research.

A comment was made about Parkinson's disease clinical research that there are often no quality of life measures in PD studies, and that the term 'disease' can feel like a negative label.

Deciding whether to participate in research

The questions of when to raise research studies, and what information to provide, were discussed:

- A professional approach from the researchers; being fully informed, given honest information about pro's and con's, a one-to-one full explanation in language that is easily understood but not patronising – getting the balance right. One to one was felt to be more effective than being given or sent an information sheet.
- Questions being answered honestly.
- What invasive procedures are involved?
- What if it doesn't work? Is it ever likely that compensation would be offered if things went wrong?

Being approached at the point of diagnosis definitely requires a skilled assessment as to whether this is appropriate at that time, and proper explanation. Neurology Specialist Nurses can often be the right person for this task, after diagnosis has been absorbed.

Practicalities

Study designers must think much more of the logistics and practicalities for patients and carers. Seeing researchers in own home was recommended as helpful.

Clear information about reimbursement of expenses was seen as important. Payment for participation was also supported in the group.

- What happens after a test, getting home etc?
- Getting there in the first place – is it inconvenient or confusing.
- How much is it going to cost me?
- Having or needing someone with you before, during or after and having that made very clear, as this then impacts upon someone else's life.

Carer issues

- A key recommendation to improve uptake of research (including the PD-Med study discussed as one example) is to acknowledge the burden on carers, where research may be an extra load to carry, often at a time in the disease process where they may be in the worst position to contribute.
- Carers would therefore need a full explanation about what is expected throughout the life of the study, who to contact out-of-hours, etc.

- Research information for carers should also be integral, often right from the point of diagnosis, and with serious thought given to how research information becomes “part of the journey”. It was also considered vital to involve carers when designing new studies.
- Quality of life studies are as important for the carer as for the patient.

Finding out about research opportunities in the first place/research registers

It was generally agreed in this group that a database of patients and carers wanting to participate in appropriate research would be a good idea for screening. People would want a very clear, formal consent process for joining and remaining on the register/database. There was a general discussion about data protection, but most people seemed confident that this would be secure.

Patients’ and carers’ evaluation of the day

The day was well received by all participants, who had wanted the day to provide an opportunity to learn more about trial recruitment to research and about DeNDRoN, as well as being a discussion of particular issues. However, the introduction was felt to be a little too “scattergun”, and lengthy, and there should have been more time for small group discussions, and group work. Similar events in the future should have a shorter introduction; with brief written information only about DeNDRoN structures. This would allow for more time for questions, discussions and small group work.

The future for the patient/carers panel – what next?

Many present were prepared to contribute to future patient/carers panel discussions and wanted updates on local research and Patient & Public involvement (PPI) opportunities.

We would like your views on how this may best be achieved and will be writing to you again in the near future with the first edition of a bi-monthly PPI ‘newsletter’, where you will be invited to contribute to finding the best ways for us to remain in contact with each other, and explore further sharing of ideas.

There is clearly an issue about how the panel would contribute to work around study delivery and/or study development. There’s also the question of how the panel should link with the LRN Steering Committee. Thoughts around this are a ‘work-in-progress’, and considered a joint learning process.

Very many thanks to all those who contributed on the day.

Juni West – Research Nurse
Terry McGrath – National DeNDRoN PPI Co-ordinator
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