



PRIMARY CARE SCIENCES
ARTHRITIS RESEARCH UK PRIMARY CARE CENTRE

VU – KEELE EXCHANGE PROGRAMME

ARMA REPORT

NOVEMBER 2011

REPORT TO ARMA – EULAR FUNDED VISIT TO NETHERLANDS

The Arthritis Research UK Primary Care Centre at Keele applied to EULAR under the umbrella of the ARMA organisation for funding to arrange an educational visit to the Netherlands by 2 members of its Research User Group - Carol Rhodes and Adele Higginbottom. Carol is the PPI (Patient and Public Involvement) Coordinator and Adele is a User Support Worker. They are both patients with fibromyalgia, a musculoskeletal condition and are members of the local ARMA group.

The purpose of the visit was to learn more about how members of patient organisations work with researchers in the Netherlands. The visit was arranged by Professor Tineke Abma who specialises in client participation including patient research partners, along with Maarten de Wit, a member of the OMERACT patient panel and author of the Dutch Handbook of Patient Participation in Scientific Research. He is also a volunteer for the Dutch Reumapatiëntenbond, the collaborating teaching organisation in this EULAR exchange program.

The visit had four learning objectives

- To understand how patients can become co researchers whilst maintaining the patient perspective
- To learn about the process and practice of patient involvement in outcome measurement
- To identify opportunities for training of research users
- To learn about recruitment and participation of a wide range of people to patient groups.

The first day's session was attended by members of patient groups from the Dutch Arthritis Network, the Dutch Parkinson Association and the Dutch Heart Association, who had worked as research partners. See attached Participants List

The programme on the first day commenced with a presentation by Tineke on Approaches to Participation – the Dialogue Model.

She explained that the Dutch Clinical Trial Foundation wanted to engage patients to help in running trials. She pointed out that Maarten c.s. had written a handbook in Dutch on 'Patient Participation in Scientific Research'.

She felt that patient participation should involve equal partnerships that can generate creativity and action to produce new ideas.

Patients should not just be viewed as consumers making choices about their healthcare but rather as citizens who had a voice to represent their communities.

Within the dialogue model she noted that dialogue between patients and professionals could produce difficult or argumentative discussions, however when patients are listened to they can be used to search for different solutions.

Knowledge can be developed from stories so a shift from subjective knowledge to collective knowledge can be made.

Enclave Deliberation is used in political science to address the needs of minority groups. It tries to create a safe space where marginalized groups can freely exchange their views without professionals present. This helps them gain a sense of community and grow power from within

This is important because there needs to be a proportional deliberation in dialogues between these groups, achieving a balance, or else established groups will always dominate the marginalised groups. For example, in health research, professionals often dominate. This has been found to be particularly important in research on the elderly and those with a psychiatric illness.

Experiential knowledge should not be seen as less valid, or less relevant – or as just anecdotal, subjective, and just the person's own viewpoint.

There are three forms of knowledge

- Being familiar with - You have experience of being ill
- Knowing how - You know how to deal with how the disease affects you
- Knowing that - The cause and effect – if you do that the outcome will be

Patients start at the top of this list and work down through it, whereas professionals start at the bottom and work backwards up the list

At this point the RADA wheel was introduced which had been designed by Parkinson's patients and researchers. This showed how different areas of life all interacted to affect the progress of the disease.

She then discussed empowerment. Empowerment suggests that power can be given so then it can also be taken back. This is a zero sum game – a power battle with one winner and one loser.

In Relational, Mutual Empowerment, all can grow and gain strength. It becomes apparent that professionals also have their vulnerabilities, so both the patients and the professionals can grow together.

Involvement can have both a beneficial, personal and collective effect.

Critique of patient participation as it stands now

There are presently 2 types of groups involved in patient participation

The patient groups representing better known conditions– from charities such as cancer research and heart research who will better manage the challenges of patient participation as there will be more support available to them.

Against the smaller more vulnerable groups for conditions such as Parkinson's who could find themselves overburdened by being involved in patient participation in research.

Both groups may also suffer from general patient participation issues – such as a feeling of tokenism and frustration if the project ends, the relationships end and they feel nothing has changed.

There are also Structural Barriers to participation

Researchers wonder why they should work with patients. Researchers are judged on their publications yet they can't publish on what the patients want.

This again causes asymmetric relationships.

Tineka concluded by saying that the cultural change needed is big and will take 20 years or more to get the balance right.

This was then followed by a presentation by Carol outlining the history of the Research User Group and the Virtual Panel at Keele, how they had been selected and a brief review of some of the research projects the groups were involved in.

Adele as an original member of the group then gave her story – sharing with the audience, just what a positive effect being involved in the Research User Group had had on her life.

All three presentations led to a lot of questions and discussion amongst the group.

Then Marianne Krijgsman gave a brief review of the Dutch Network of Arthritis Research Partners. Marianne explained that her job was to pull together a panel of patient research partners that the network could draw from, in order to have a patient input within their projects.

Wijnanda Hoogland then gave an account of her work as a patient research partner with Arthritis Network. Wijnanda had helped to co-author a paper entitled: Patient perspective on remission in Rheumatoid Arthritis which discussed the workshop set up at OMERACT to investigate the patient perspective on remission.

In the afternoon we split into two groups to discuss 4 themes

- Selection and Recruitment
- Levels of Involvement

- Training
- Diversity and Representativeness

However due to shortage of time we felt it best to concentrate on two themes that highlighted the similarities and differences in our approaches to patient participation in research:

These were

- Selection and Recruitment
- Diversity and Representativeness

Both Willem Leedekerken who is also pulling together a list of selection criteria for a patient panel for the Dutch Parkinson Association and Marianne were keen to get some input on what should and what should not be listed as essential selection criteria for a research patient partner.

This discussion highlighted some key differences in recruitment between the model used at Keele in England to select their group and the standard practices of patient groups in the Netherlands.

The members of patient groups around the table had been recruited after reading advertisements on their group's website asking for patients to become more involved in research. These ads had very similar selection criteria.

These included

- Being able to see things objectively
- To have a familiarity with the disease being researched
- To attend for a period of up to 2 years
- To have an interest in research
- To have a certain level of education – i.e. degree level
- To be able to travel alone.

The patients were then invited to an interview with the research panel members who had the final choice in who was recruited.

This was very different to the models of recruitment that Keele University had used. Carol and Adele had previously described 2 groups using different methods.

- The RUG - The original research user group made up of 8 members who had been contacted due to their acting as participants in research trials. So they were invited by researchers.

- The Virtual Panel – A group of patients sourced from a large letter drop sent to patients by their GPs with just one preselection criterion, that they had a musculoskeletal condition. They were invited to a launch meeting for patients interested in getting involved in research. So the research team had no prior knowledge of the backgrounds of the people making up this panel. There were no interviews and all were welcome to become a part of the panel

When recruiting the Virtual Panel, after listening to advice from the original research user group, Keele specifically employed a patient to work with researchers in the role of user support worker in order to be able to manage and support the needs of the individual patients within their groups. In the discussion it was also noted that patients can be involved in research for different reasons which may affect the method of selection used. These included:

- Ethical reasons;
- A need to improve the content of the research depending on the level of input sought. It was noted that there is a difference in roles, between involvement in consultation and advice and collaboration as a research partner. Some patients attend workshops and present at international conferences so it was argued that they would need a certain level of education.
- Political reasons: For instance selecting representatives from national patient organisation to guarantee chances for implementation and dissemination.

This was followed by a counter argument that all types of patient can be involved in research so long as they are offered the right level of support and training if required.

- This led to thoughts on using selection criteria asking for people who were Willing to travel – although the point was made that funding should be made available to make sure that this was not alone as specified on one website, but rather accompanied by a researcher, another patient or a carer or family member.

Willing to learn about research / Willing to be trained if needed – Adele when telling her story made the point that she had left school without further education and so she would not have been considered for recruitment, if the selection criterion on education had been used. Yet, she had now been involved in many different research projects carrying out a range of activities, including attending and presenting at leading conferences throughout the UK.

On the following day a different group of patient research partners attended from the Dutch Heart Association and the Arthritis Network.

The session commenced with a presentation by researcher Merel Visse on her expectations and responsibilities of being a project leader on a project with a patient research partner researching the psychological effects of heart attacks.

From her experience Merel reflected that one of the selection criteria for her project that she felt was the most important was that of

- The ability to reflect from a distance

She explained that when talking with potential recruits she found that a lot of them were still very emotionally involved in their own stories and therefore not able to look at things or reflect from a distance.

Research partners were paid a modest salary which Bob her co presenter thought showed that his work was valued. The patients were trained in areas such as the management of expectations, the responsibilities of the project leader, understanding bias and the value of experiential knowledge vs. scientific knowledge.

The team also had regular meetings every 6 weeks.

The patients conducted the interviews with the participants alongside the researchers. They worked from a topic list and it was felt that participants had responded well to the patients conducting part of the interviews by discussing things with them that they may not have discussed just with the researcher alone. The research partner and researcher travelled together to the participant's homes so they had a lot of informal meetings where they had long conversations about the roles of scientific researchers and project leaders. The partners were then also involved in the analysis of the interview scripts. All of the team were very proud to win an award from Zon Mw for their poster on the results of the project.

Merel said that she saw research as a social practice, where everyone should be involved and knowledge could be diffused backwards and forwards. She felt that it should be congruent with reality and stimulate critical thinking. Research partners could be critical companions taking on an ambassador role, influencing the research outcome.

One of the issues she raised was whether any bias was introduced into the data by using patient research partners. However Maarten commented '*should this be seen as bias or rather as enrichment of perspectives?*'

A comment heartily agreed with by the patients around the table.

This presentation was then followed by some interesting group work, in which Merel spread out a lot of different photos on the table and then asked each member of the group to pick a picture that portrayed for them how it felt to be a research partner.

Each partner then explained to the group why they had chosen that particular image. This produced some very interesting insights into how people felt about their role.

They were then asked to write their personal story – so *‘once upon a time I became a research partner...’*

This group activity was quite inspirational as it became apparent what an effect becoming a research partner had had on their lives.

Bob Roukema then gave a presentation on why he had decided to get involved in a research project on heart disease. He started by telling his own story of how while on holiday in Croatia with his family he had had a heart attack. He had to leave his children behind and be driven for 2 hours into a war zone to find medics that could treat him.

This experience had a deep psychological effect on him long after his heart condition was stabilized. So he was very interested in a call for heart patients within the heart patient association to get involved in a research project on the psychological effects of heart attacks.

It had taken him a long time to get his confidence back, but now helped by his work as a research partner he had finally revisited the exact spot in Croatia where he had had his heart attack. This was obviously a major step forward in dealing with the last remaining effects of his heart attack on his life and also a great personal achievement.

This was followed by a very poignant session by Willem Leederken about his story of being the husband and carer of an early stage Parkinson patient and how this had led him to become involved with the Dutch Parkinson association and how his activities had enriched his life.

Willem had previously worked as a psychologist. After his wife's diagnosis he had joined the Parkinson association as a volunteer and had answered a call on their website to get involved in a project to find out what Parkinson patients thought were important research questions. This project was initially rejected for funding, but after nearly 2 years of lobbying, funding of 100,000 euro's was finally obtained. Willem felt that the main barrier had been that the funding association did not understand the importance of qualitative investigation.

In May 2010 research partners: Willem, Henk Dellebeke and Lizette van de Moosdijk joined the research team. They were involved in all stages of the research process except for the writing of the protocol. They travelled all over the country to take part

in interviewing the participants along with a project researcher. They took part in many project team meetings and focus groups. They helped in the analysis of the transcripts and also in the development of a questionnaire for quantitative analysis.

Willem is now a member of the Parkinson's Association Scientific Society which assesses applications for research funding. He is currently involved in producing guidelines and selection criteria for a panel of patient partners.

Henk van Duyn then gave a presentation on his experiences of working as a research partner with the Dutch Arthritis network.

Henk told of his experience of being a research partner along with Andrea Evers, a Professor of Medical Psychology, on a project on 'Cognitive Therapy for Rheumatoid Arthritis and Psoriasis'. Participants were asked to record their levels of coping with pain and depression on a weekly basis. These were then discussed with their specialist. The result of this activity was to show that more people than expected needed some mild psychological help.

The project involved developing a set of interventions that patients could access for themselves over the internet – linked to a psychologist.

Henk was not too impressed with the idea of cognitive behaviour therapy, but tried the intervention – as a “test subject” or “fake patient” - to see if it worked. As you cannot fake your problems he realised that he too had real issues with work, depression and fatigue. But more importantly he realised that this programme really worked!

He took part in what was to become an emerging design. At one of the team meetings a patient partner who worked in software warned the team that the layout of the website would not work and the original software had to be thrown out. This caused a delay of three months. A survey showed that 85% of patients were on the internet and so would be able to access this programme.

A suggestion was made that some of the patient partners could act as a virtual help desk to help participants who had problems using the web page. However, it was thought that this would lead to ethical issues of confidentiality, so was not able to take place.

Henk did not receive payment for his work but still felt that his input was acknowledged as he was given access to software at a reduced rate and access to the university library. He also enjoyed being taken out for a team meal twice a year.

Maarten concluded the session by thanking everyone for their input and by summarising the similarities and differences in approaches to PPI that we had all presented.

Areas such as training had only just been touched on and it was felt that further correspondence on these issues would be needed.

Everyone in attendance felt that they had had a really enriching and educational experience.

**Participants list VU-Keele Exchange Programme
(September 29 and 30, 2011)**

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