

Public involvement in health research in the North West

Report of the Success Stories mapping project and conference 2005/6

The North West User Research Advisory Group
in conjunction with
Health R&D North West
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The Success Stories mapping project

Background

Health R&D North West (HRDNoW) is a Department of Health funded research and development support unit for the North West of England, covering the area from North Cumbria down to Cheshire. In 2000 the unit began working to help the development of service user and carer involvement in health research. Several conferences and seminars were held and an advisory group was set up for the region. The group consists of both lay members and professional health researchers and is supported by HRDNoW.

The main aim of the North West Users Research Advisory Group (NWURAG) is to encourage and support the active involvement of members of the public, service users and/or carers in any and all aspects of health-related research in the North West region. To do this we undertake a variety of activities, one of which has been to gather and disseminate 'success stories' about research activities involving the public, service users and/or carers that have taken, or are taking, place in the North West.

Aims of the project

The aim of the 'success stories' project was twofold: to map and to publicise user involvement research activities across the North West. In doing this we aimed to provide good examples of the practice and to create a resource of people with expertise in this activity. We also hoped that the exercise would encourage by example and so planned to publicise the results through this report and a 'showcase' event.

Method

In May 2005 a survey form (see Appendix 1) was designed and distributed widely across the North West region. It was sent to all North West R&D managers in Trusts and to those people who had contact with HRDNoW about user involvement. It was also advertised on HRDNoW's website and in the newsletter, in the North West region's Patient and Public Involvement (PPI) Forum newsletter, on the Royal College of Nursing Research and Development's electronic bulletin, and through CHAIN².

Results

In all 21 completed forms were returned, and all bar one were happy to have their projects and contact details made public. A summary of each project is given in Appendix 2. Projects were fairly equally spread across the region. Six came from Cheshire and Merseyside, six from Greater Manchester and eight from Lancashire & Cumbria, with one additional national project. Several projects mentioned sites in addition to the North West where the research was

² Contact, Help, Advice and Information Networks <http://chain.ulcc.ac.uk/chain/index.html>

taking place (Sheffield, Chesterfield, Uganda). Thirteen projects were ongoing, and eight were either already finished or due to end in 2005.

The numbers of lay people involved in each project were very variable. Five projects reported large numbers, but these counted the research respondents and as such are classed as passive involvement. However, the researchers felt the projects had potential to benefit users, e.g. through expressing themselves in focus groups; gaining improved services.

Eighteen projects reported active involvement with between 2 and 50 lay people involved in the research process. A few were in the process of setting up and did not have clear figures of numbers involved. Distinctions were made between the different roles that lay people could have in the research, and the ways in which lay people were involved were various. It was encouraging to see that nine of the projects had lay people involved at all stages of the research process. The kind of roles for lay people that were described included:

- Advisors on research proposals
- Helping with design
- Peer reviewers
- Members of project steering group
- Research management roles
- Data collection
- Participants (interviews, focus groups, questionnaires)
- Dissemination

The topics of the studies also covered a wide range:

- Childbirth, children and parenting - 5
- Mental health - 4
- Service development and evaluation (nursing; multi-agency; occupational therapy) - 4
- Community engagement - 3
- Older age - 2
- Sexuality - 1
- Quality of life after injury - 1
- Learning disabilities - 1

All the studies used questionnaire or qualitative methodologies, such as interviews and focus groups, and a few respondents mentioned specific methodologies (e.g. appreciative enquiry; evaluation; oral history; mapping surveys). Two studies specifically mentioned training sessions in research for the lay people involved.

The benefits of lay involvement

There were two questions in our survey that asked about the benefits of lay involvement. The first asked specifically about benefits to the people involved: "Please describe any tangible benefits for the people involved in the project". In our guidance notes for the question we suggested:

For example:

- What was the benefit of lay involvement for the service user/carer?
- What was the benefit of lay involvement for the academic/health professional?

In the main those reporting on the projects wrote only about benefits to the lay people involved, and only one or two mentioned benefits for the professionals. In the context of the survey the focus on the lay members of the team was understandable, but it is noteworthy that the assumption was that the lay people would be the main beneficiaries. It is important to remember that the experience of public involvement in research should ideally be a two-way process. If we had asked two questions, along the lines of those above, but focusing specifically on the benefits for professionals/researchers, we may have captured more on their experiences.

As listed below, the perceived and anticipated benefits for lay members of the team were many. Personal development figured largely, but a sense of benefit to the community as a whole and contribution to improvement of services was also noted. Many of the factors indicated by our respondents are in line with those cited in the literature.³

For the lay people involved:

- Skills development (e.g. research, communication, database) - 9
- Confidence building - 6
- Making a difference to services - 6
- Learning (e.g. about research and organisations) - 6
- Feeling valued and being heard - 5
- Social contact and sharing - 3
- Work type experience, potential employability - 2
- Ownership and a sense of control - 2
- Engendering community spirit - 2
- Personal challenge - 1
- Time to reflect - 1
- Better working relationships with staff - 1
- Less invasive treatment - 1
- Payment - 1
- Pleasure - 1
- Continuity (continuing on to get funding) – 1

For the professionals:

- Opportunities for change in practice - 2
- Insight – 1
- Pleasure – 1

³ E.g. Barnard, A et al (2005) An evaluation of consumer involvement in the London Primary Care Studies Programme. INVOLVE

One respondent quoted a lay person:

"It improved our confidence, and skills in research. It gave us a sense of ownership of the project and challenged us both mentally".

Another described her own feelings as the main investigator:

"For the researcher the benefits were that I got a truly child's-eye view of the service. It was really enjoyable but somewhat chaotic and unpredictable."

The second question asked about the benefits to the project. Again the respondents came up with many perceived advantages, as listed here:

- Relevant to user concerns - 5
- Methodologically helpful (e.g. developing instrument, taking new directions, more valid) - 5
- Interview data collection (e.g. rapport, support, equality, different perspective of lay researchers) - 5
- Expert/insider knowledge accessed (e.g. input from 'hard to reach groups') - 5
- Dissemination (e.g. commitment to, more appropriate, wider) - 3
- Service improvement (e.g. more targeted) - 2
- Optimism about research - 2
- Diversity - 1
- Creativity – 1

It was notable that the comments about benefits to the project echoed the commonly cited theoretical reasons for involvement, such as those at the INVOLVE⁴ website.

Additional comments

The survey form offered respondents the chance to add any additional comments. Not all of them did and some were related to further information about the project, but several did take the opportunity to reflect on the overall experience and their own learning, e.g.:

"The perspective gained from having the associate researchers was invaluable, and their previous level of research skills enabled us to have some active and open debates."

"The success of this small scale project with children gave me additional confidence for undertaking larger scale projects with co-involvement right from the start."

"This project has been successful by enabling professional and lay people to gain confidence and skills through, developing a good working relationship; producing results which would not have been reached without lay involvement and getting the needs and wants of older people back to those who deliver the service."

⁴ See, for example: http://www.invo.org.uk/Why_Public.asp (last accessed 1/3/06)

All contributors to the survey were invited to submit an abstract for our showcase conference, which is described below.

The conference

HRDNoW agreed to fund a one-day regional conference for the success stories project, which took place at the Woodlands Conference Centre in Chorley on 3rd February 2006. The conference was free to delegates, who received a certificate of attendance and administrative support was provided by HRDNoW. A sub-group of NWURAG, consisting of eight members met three times to design and plan the conference. The sub-group wanted the conference to showcase local projects and also to provide a space for workshops and networking.

Nine of the projects in the survey submitted abstracts for oral presentation at the conference. The group met to consider these, and seven projects (one national project and six North West regional ones) were invited to give presentations. The criteria for acceptance were:

- ◆ Users actively involved in the research process
- ◆ Projects which are well underway or completed
- ◆ Variety of subject matter and method
- ◆ Whether a lay co-presenter is mentioned

In addition we invited poster presentations from other projects known to us, some of whom had not completed the survey form, and nine projects provided posters. For our plenary speaker we were fortunate in securing the services of Sally Crowe of the James Lind Alliance, an organisation whose aims are in line with ours in seeking partnership between lay and professional researchers in health. We also had four display stands: INVOLVE, RDLearning, the Black Health Agency and the Patient & Public Involvement in Health (PPIH) Forum.

The conference was chaired by NWURAG's lay Chair (Sue Hinder). The workshops were facilitated by lay members of NWURAG (David Britt, Sue Hinder and Gary Young). Note-taking and general support was provided by HRDNoW R&D managers and staff (Vicki Bell, Catherine Gedling, Ruth Hunter, Sara Morris and Tim Twelvetree). All lay presenters and facilitators were paid a fee, and their expenses were reimbursed.

The conference was advertised in November 2005 and was fully booked by December. Despite our decision to raise the numbers, limited capacity meant that more than 50 people had to be placed on a reserve list. On the day 72 of the 80 booked delegates attended, along with the eight NWURAG/HRDNoW organisers and four people with display stands. Of our attendees 25 were service users/carers, 35 were NHS employees and 12 came from academia or elsewhere.

Content of the conference

The presentations

We asked that where possible a lay and professional member of the research team should present and accompany poster presentations, and this was achieved in the majority of cases, with 5 of our 13 speakers being lay researchers, and 4 lay people attending with posters. The lay presenters delivered interesting reflections on their involvement and were especially well received by the delegates. A wide range of research topics were covered in the presentations – all with an emphasis on the ways in which service users and carers had been involved and the contribution they had made to the success of the project. The abstracts for the talks and posters are included in Appendix 3.

We also allowed time for discussion in workshops following the oral presentations (see Appendix 4 for the conference programme). The workshops were arranged to allow people to split into three groups and discuss the issues raised by the six local projects.

The workshops

Each workshop was facilitated by a member of NWURAG and notes were taken by Health R&D staff. The workshops offered an opportunity for questions about the specific project and a chance for further discussion. In all the workshops questions about the practicalities of the project were asked, such as how the lay people had been contacted by the professionals, how much training had been given, where meetings had been held.

Issues raised by public involvement were also discussed in the workshops. Some items of good practice and some challenges were highlighted – they were (in no particular order):

- having pre-existing connections through other work with relevant groups helps;
- it was considered important to have lay people involved at beginning of a study;
- training provides valuable insight into how research is done for the lay people, and can lead to respect for the expertise of the researchers, as well as pleasure in learning;
- it was considered important to empower the volunteer researchers;
- it was considered important that the professionals respect the knowledge of the volunteers and listen to them;
- it is helpful to look toward the positive, rather than dwell on any problems;
- it is helpful to dispense with any 'pre-agendas';
- it is important to have some quality control measures in place;
- accessibility issues need to be discussed from the outset – local knowledge is very important in identifying ways to maximise participation (e.g. local meetings at appropriate times);

- certain types of involvement really benefit from links with the relevant NHS Trust R&D manager and Patient's Forum;
- it is possible for a lay group to have an input into the research priorities of an organisation;
- people learn as they go along;
- there may be risks and challenges to the professional role, which could include 'de-skilling' and emotional issues;
- it can be a challenge for the professional to manage the research process with volunteers while keeping the quality of the research in mind all the time.

Evaluation

What did you like best about the conference?

User Involvement

- Contribution of service users to the presentations and workshops
- Involvement of the users. Including their perspectives and not just the researchers sharing their practice
- Opportunity to find out more about user involvement
- Examples of how user involvement can work throughout the research process
- An enjoyable day, I am so impressed by the level of user involvement in research in the region, and the enthusiasm and commitment HRDN has for promoting user involvement

Atmosphere

- Mix of audience and presenters
- Friendliness and gathering of information
- Positive focus and sitting at tables in groups
- Excellent mix of 'professionals' and patients/public – best one I that I've attended of its kind
- A lot of chances to chat to people, nice surroundings

Networking

- Networking, meeting people who could help me as a novice researcher, and learning about others' successes
- Networking opportunities
- Making new contacts
- The networking opportunity, the group seemed to mingle well

Presentations/Workshops

- The project presentations (x4)
- Wide variety of research projects (x2)
- Variety of subjects covered (x3)
- Sally Crowe's presentation: very varied research projects presented, able to hear a bit about these
- Workshops that allowed more time to explore presentation issues

Learning

- Funding information via Lottery was useful
- Learning
- Hearing about a wide variety of projects and finding out that things worked, gave positive message.
- Very worthwhile, learned a lot. The common aim of the attendees came across very well

The conference was well received and the 49 evaluation forms returned made for positive reading. All aspects of the conference were rated by the vast majority as 'excellent' or 'very good', with a few 'good's and only one 'poor' (for

the catering). A summary of the evaluation ratings are included as Appendix 5. There was plenty of space on the form for comments and a few of the more common ones are set out in Box 1 below.

On the evaluation form we asked what could be done to improve the conference. A gratifying number of responses said 'nothing', that it would be 'very difficult to improve on well oiled wheels'. Some people suggested improvements for the venue and catering, and others suggested that time-keeping in the afternoon sessions could have been tightened up. Although many felt the opportunity for meeting others and discussion was good, others recommended more workshop/interaction time, e.g. 'Larger periods for networking, please could we also have some 'hot topic' sessions'; 'Would have preferred a greater involvement, i.e. more two way questions and answers therefore less presentation'.

Concluding remarks

We are fortunate in the HRDNoW in having been involved in 'user involvement' work for some time and in having a committed group of lay and professionals who support this work. The process of gathering information about local projects and show-casing them, as described in this report, has been a very interesting and helpful exercise. The interest in the conference was perhaps an indicator that the work was particularly timely. We plan to continue our work in disseminating, encouraging and supporting the involvement of the public in the processes of health research.

If you want to learn more

www.hrdn.org

We provide support for people wishing to involve Service Users in their research, and support for Service Users who wish to become involved in health research (including individual advice and workshops for both NHS staff and Service Users).

www.invo.org.uk

INVOLVE is a national advisory Group, funded by the Department of Health, which aims to promote and support active public involvement in NHS, public health and social care research.

www.mhrn.info/dnn

SURGE is the Service User Research Group in England and is the service user arm of the UK-Mental Health Research Network (MHRN). SURGE is a national network set up to support mental health service users and people from universities and NHS trusts, as they work together on mental health research.

Appendix 1: NWURAG Research Success1 Stories form

Please complete this form and return it to Sara Morris. Please use additional sheets and attachments if needed. Guidance notes are provided on the final page.

CONTACT PERSON DETAILS²	
Name:	
Job title:	
Organisation:	
Address:	
Email:	
Phone:	
Are you willing for your contact details to be made public?³	
Yes <input type="checkbox"/>	No <input type="checkbox"/>

[Health R&D North West Data Protection Statement included here]

PROJECT DETAILS	
Name of research project:	
Location of the project (e.g. nearest town/district):	
When did the project start?	
When did the project finish (if applicable)?	
How many service users/carers/lay people participated in the project?	
In what ways were they involved?	
Please provide a short lay summary of the project, including aims:⁴	
Please describe any tangible <u>benefits for the people</u> involved in the project:⁵	
Please describe any tangible <u>benefits to the project</u> arising from the involvement of service users/carers/lay people:⁶	
Any additional comments:	

NOTES:

1. By 'success' we mean any aspect of lay people's involvement with research that has worked well. Some possible examples:

- professional or lay people gaining confidence/skills;
- mutual learning;
- innovation;
- developing good working relationships;
- accessing 'hard to reach' groups;
- producing results which might have not been reached without lay involvement;
- getting the message back to the people who use or deliver services;
- improving services;
- and any other possibilities we haven't thought of!

2. You may be contacted by a member of NWURAG by telephone for further discussion and clarification as appropriate.

3. We aim to publicise local success stories about lay involvement in research on our website, in the information we produce and in the talks we give. In this way we hope to encourage people to consider involving users in their research. We will keep names and institutional details confidential if you prefer.

4. Please feel free to attach any existing documents you have that you feel would be helpful in describing the project. For example, an information sheet or lay summary.

5. For example:

- What was the benefit of lay involvement for the service user/carer?
- What was the benefit of lay involvement for the academic/health professional?

6. For example:

- What was the benefit of lay involvement to the project's design and methodology?
- What was the benefit of lay involvement to the project's analysis and dissemination?
- What was the benefit of lay involvement for the future provision of healthcare in your particular research field?

THANK YOU

Please return either a paper copy by post, or save the completed form on your computer and then attach it in an email. Send to:

Dr Sara Morris, R&D Manager for User Involvement, Institute for Health Research, Bowland Tower East, Lancaster University, Lancaster LA1 4YT

Telephone: 01524 592656 Fax: 01524 592401 Email: s.m.morris@lancaster.ac.uk

Appendix 2: Summaries of projects

Contact	Research project	Summary
Brian Bennett brian.bennett@merseycare.nhs.uk	Qualitative exploratory study of service users experiences of being a research participant in a high secure hospital	This is a qualitative investigation into the impact research participation has on an individual in high secure services. Its aim is to look at what it is like to be involved in research, how the participant felt they were being treated at all stages of the project by the researchers, staff, and other patients. The intention is to develop some guidelines for researchers about how they should approach and treat participants in this setting and also to provide information to patients about what they can expect when approached to take part in a project
Bernadette Carter bcarter@uclan.ac.uk	Children's and their siblings' perceptions of the Diana Children's Nursing Team in Salford	The study aimed to find out children's perspectives of a Diana Nursing Service; what they liked about it, what they didn't like about it, what they'd like to change and what they'd like to see happen in the future.
Bernadette Carter bcarter@uclan.ac.uk	Appreciating the best: multi-agency working practice project	The purpose of this project is to explore and disseminate the best multi-agency working practice associated with children with complex health care needs and thus promote child-friendly services through Cumbria and Lancashire. An outcome of this project will be the development of guidance plans for best multi-agency working practice with children with complex needs. It is expected that these guidance plans will have transferability to other children requiring multi-agency care. This proposal has been designed in line with the principles that underpin the work of the WDC Care of Children Group. The aims of this project are to: 1. engage with children and their parents/carers and with the people (from as many agencies as possible) who are involved in working with children with complex needs; 2. appreciatively explore examples of best multi-agency working practice so as to determine what works well, why it has worked

<p>Beverley Gibson beverley.gibson@lancashirecare.nhs.uk</p>	<p>R&D Service User/Carer Working Group</p>	<p>well and what best practice in future could be; 3. create opportunities, networks and guidance plans that will help support and enhance multi-agency working practice and organisational development throughout Cumbria and Lancashire.</p> <p>The project started in May 2004, where service user and carer groups from Lancashire were invited to attend a workshop about R&D in Lancashire Care NHS Trust, they were asked to do group work about how they would like to be involved in R&D in the Trust. People who were interested further were asked to write their names down so be contacted at a later date regarding a training workshop. The training workshop took place in Jan 2005, where training on reading and critiquing research applications was given. From this training session 6 users/carers expressed an interest in being a member of the R&D Service User and Carer Working Group, to work alongside the Research Governance Sub-Committee.</p>
<p>Fiona Greenwood C.F.Greenwood@salford.ac.uk</p>	<p>The "Saying Hello" project</p>	<p>Aims to identify and promote strategies for coping with, and reducing, social isolation and loneliness amongst older people in Wigan Borough. The project is a collaboration between the University of Salford, Age Concern and a volunteer researcher group recruited to conduct the research.</p>
<p>Julia Herbert julia.herbert@bolton.nhs.uk</p>	<p>Anal incontinence - a consequence of vaginal delivery</p>	<p>Recently a female patient shared with me her experiences of having anal incontinence as a result of a birthing injury sustained at the delivery of her first son 24 years ago. During this delivery she suffered a severe tear of the muscles that control the anus. As a result of this injury she became unable to control her bowels and regularly suffered from episodes of anal incontinence being unable to hold on when she needed to pass wind or empty her bowels. She found dealing with these symptoms extremely embarrassing and they impacted on all aspects of her life including work and personal relationships. The saddest part of her experience was that despite finding the</p>

<p>Joanne Inman Joanne.inman@lancashire.nhs.uk</p>	<p>Is Vocational Rehabilitation a Transition to Recovery</p>	<p>courage to mention these devastating symptoms to healthcare professionals, on more than one occasion, she was never investigated and was simply told that she probably had irritable bowel syndrome. Some 20 years later she finally had investigations that revealed the damage to her anal muscles and she had corrective surgery.</p> <p>Listening to this lady's history made me start to analyse whether her experience could still be repeated with the continence services currently provided in this locality for post natal women.</p> <p>The purpose of this investigation is to evaluate the current service provided by the local integrated Continence Team for post-natal women who have experienced obstetric trauma to the anal sphincter at delivery.</p> <p>The study population will be obtained using the delivery register at the maternity unit and will include all women who have sustained a third degree obstetric tear at delivery in the last five years.</p> <p>The research will then be conducted in two stages. Firstly women consenting to take part will be sent a validated Manchester Health Questionnaire (Bugg, 2001) to establish the prevalence of anal incontinence and it's affect on their quality of life.</p> <p>Secondly, three groups of 12 women will be invited to take part in focus group interviews to obtain richer data about their experiences following delivery and what they feel should ideally be provided by the integrated continence service. The focus group interviews will be held at local health centres to enable easy access and crèche facilities will be available.</p> <p>This study aimed to explore the recovery experiences of service users with severe and enduring mental health problems in relation to a Vocational Rehabilitation Scheme. Two associate</p>
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	<p>for Individuals with Severe and Enduring Mental Health Problems?</p>	<p>researchers who were also service users were an integral part of the study throughout. A qualitative research method was used: twelve service users (participants) who were working on the Scheme at the time of the study were asked about their work skills, quality of life and transitions to work. The data was analysed and coded into themes. The Vocational Rehabilitation Scheme was identified as enabling participants to move on from; passive to active; illness to well-being and negative to positive thinking. It was also seen as a catalyst to change in other areas of the participants' lives. Actual specific work skills proved to be the least significant transition. The study indicated that the Scheme contributed to participants' recovery and may be enhanced by developing vocational opportunities outside the NHS.</p>
<p>Christine Johnstone peter.johnstone5@virgin.net</p>	<p>The Needs and Wants of Older People from the NHS</p>	<p>The aim was to bring to the attention of the North Cumbria NHS the concerns, wants and needs of older people in the context of the Elderly Care Critical Enabling Project. Project Summary: It is the duty of the NHS to consult with patient and Public Information forums (PPIs) on any alterations to the health service. I was requested to "Find the Needs and Wants" of older people from their health service. Please see the attached questionnaire for the, Public and Patient Involvement Elderly Care Critical Enabling Project.</p>
<p>Carol Kubicki carol.kubicki@prestonpct.nhs.uk</p>	<p>Preston men's health programme</p>	<p>Group work and outreach work with men in Preston to raise awareness of men's health issues and improve the health of men.</p>
<p>Geraldine Nicholson geraldine.nicholson@bwdpct.nhs.uk</p>	<p>Shaping the Future of Integrated Health and Social Services</p>	<p>The main aim of the project is to identify the evidence base for delivery of integrated health and social care, the skills and knowledge required to deliver this care, together with the current and future education and training needs of the North West of England Primary care Trust workforce. This will take account of the NHS Modernisation agenda and the needs of the independent sector as it interfaces with social, community and</p>

<p>Liz Pitt liz.pitt@psychology.bstmht.nhs.uk</p> <p>Cathy Robertson cathy.robertson@ntlworld.com</p>	<p>User led research on recovery from psychosis</p> <p>(provisional title) Service user involvement in the evaluation and development of the acute occupational therapy service in Wirral Hospital NHS Trust</p>	<p>primary care. As this is very complex project involving a collaboration of higher Education institutions and Universities across the North West I have included a web address http://www.pcet.org.uk/publications/ProjectSummary(rtf).rtfThe remit at the University of Central Lancashire was to consider Service User involvement. We needed to gain the views of people accessing services and/or their carers about the health and social care services they received. This looked at their satisfaction with health and social care services, if and in what way they felt they might like to be involved in the training of service providers, also how well the services integrated to provide their care and their finally provision was made for individuals to express</p> <p>The aim of the study was to carry out a piece of user led research looking at recovery from a user perspective. We conducted 7 semi-structured interviews with people with experience of psychosis and using mental health services and analysed the data using interpretive phenomenological analysis</p> <p>Most occupational therapy resources within the NHS are concentrated in secondary care. Occupational therapists are under pressure to work ever more effectively in a context of financial constraint and externally imposed targets. Pressure to meet these targets means that they feel unable to carry out thorough assessment, treatment and rehabilitation with their patients. Too often, their role is limited to rapid assessment, environmental risk assessment, and discharge planning, regardless of whether other patient centred goals have been addressed. WHT provides an occupational therapy service for inpatients on acute elderly, medical, surgical and orthopaedic wards, and on rehabilitation wards and specialist rehabilitation units, on three hospital sites. Service user evaluation of other occupational therapy services within the Trust is already in place. Patients who have been discharged from the Wirral</p>
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<p>Lisa Shoja Imalihi-shoja@uclan.ac.uk</p>	<p>The Comensus project. Community engagement and service user support</p>	<p>Enablement Discharge Service (WEDS) are asked to complete a questionnaire indicating whether their goals have been met and whether they are satisfied with the service provided by the WEDS team. Reported levels of satisfaction have been high, and no changes have been made to the service as a result of this feedback. The Wirral Limb Centre (WLC) regularly obtains feedback from all its service users by using questionnaires. This has included feedback about aspects of the occupational therapy service such as perception of the occupational therapist's role, the environment, and the attitude of staff. Obtaining useful service user evaluation of an acute inpatient service may be more difficult. Patients may see the occupational therapist only once or twice during an acute inpatient stay and their immediate goals may be limited to that of hospital discharge and returning home as soon as possible. In the acute setting, it may be easy for occupational therapists to assume that because they work to facilitate and enable a prompt and safe discharge from hospital, that service users must therefore be satisfied with their experience of occupational therapy. However, the relationship between a service user's expectations, experiences and satisfaction is complex (Edwards & Staniszewska 2000), and the particular context of their involvement in the health care process is a crucial factor.</p> <p>RESEARCH AIMS This research has the following aims: 1. To identify ways in which service users can become involved in the continued evaluation and development of the occupational therapy service within Wirral Hospital NHS Trust. 2. To identify what it is like to receive occupational therapy treatment as an inpatient within WHT.</p> <p>The project entails a new approach to community and service user involvement within the Faculty of Health at UCLAN. The project aims to develop curricula which are more focused on community and service user needs and concerns, access to</p>
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<p>Barbera Smith bdsmith@fsmail.net</p> <p>Sue Spiers sspiers@liv.ac.uk</p>	<p>Predictors of Health and Quality of life for persons with ventilator assistance after spinal cord injury</p> <p>Service User Involvement in Forensic Mental Health Research Commissioning</p>	<p>support systems for students who may need more peer support; better designed and more fundable research projects; and immediate access to knowledgeable community members and service users for committee and project development work. Since this will be a unique innovation, it is anticipated that the project will also generate interest from external bodies. For the local community, the project aims to enhance the employability, skills, confidence and knowledge of the community members and service users involved, and to maximise their capacity to cascade these gains into a Social Firm. Objectives: completion of a thorough mapping of the current extent and nature of community and service user involvement in the Faculty; establishment of a Faculty Community Council to oversee and contribute to involvement activity within the Faculty; realisation of external funding to initiate and develop the Social Firm. It is expected that the results of this study will: 1) clarify the nature of specific health needs associated with mechanical ventilation after spinal cord injury (SCI); 2) describe the role of caregivers and environmental variables in health, secondary complications, and quality of life outcomes; and 3) provide a foundation for targeted medical interventions and community advocacy activities.</p> <p>The aim has been to ensure that service users with a history of mental health problems and, in some cases, experience of forensic mental health services are involved in all aspects of the research commissioning process. This includes prioritisation of research topics, peer reviewing proposals and reports, selection of funded research and the dissemination of findings. This has included working with Rampton High Secure Hospital Patients Council and the Revolvers, a service user group established through The Revolving Doors Agency. The Programme has also specifically commissioned projects which are user focussed and user-led.</p>
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<p>Miranda Thurston m.thurston@chester.ac.uk</p>	<p>Developing a self-assessment toolkit to assess the parenting support needs of disabled parents</p>	<p>The aim of the research was to explore disabled parents experiences of trying to access health, education and social care provision, as well as the social services assessment process where applicable. This evidence base was then used to develop a self-assessment toolkit. The toolkit comprised a questionnaire that helped parents identify their parenting support needs. It was envisaged that this would be valuable for those who were about to undergo a social services assessment process, in that it would help them draw up a list of their priorities and needs, as well as be useful in a more general sense to help people think through what support needs they had and how they might be met.</p>
<p>Gillian Vernon g.vernon@liverpool.ac.uk</p>	<p>The Release study - umbilical vein oxytocin for the treatment of retained placenta</p>	<p>The attending midwife or doctor (Release trained), will inject oxytocin directly down the umbilical cord to the placenta. It is hoped the injection will help the placenta to deliver naturally, avoiding the need for a manual removal in theatre. Further, information about the study can be found on the study website: www.releasestudy.org</p>
<p>Karen Whittaker kwhittaker1@uclan.ac.uk</p>	<p>Sure Start Preston East Evaluation of parenting support</p>	<p>This local evaluation was developed through consultation with key stakeholders to the SSPE programme, namely the programme manager, employed team members, the management group and parents. The short-term goals that were identified from working with stakeholders are listed below. These were the need to identify:</p> <ol style="list-style-type: none"> 1. key service elements 2. key evaluation questions 3. strategies for answering questions 4. resources available for actioning the evaluation 5. the contributions to be made by stakeholders. <p>These goals were covered during three separate workshop events and from this the evaluation purpose and specific questions were identified (see study protocol). This evaluation concentrated in the main on developing an understanding of</p>

<p>Vicky Wilkinson vicky.wilkinson@halton-pct.nhs.uk</p> <p>Tracey Williamson T.Williamson@salford.ac.uk</p>	<p>Training of lay people to become community researchers in health issues</p> <p>Evaluation of nurse-led unit</p>	<p>how key services have produced outcomes. However as the first local evaluation of SSPE is provides some baseline data for ongoing evaluative work. The involvement of Sure Start team members in this process has been important not only for the thoroughness of data collection, but also for normalising the practice of evaluation. This in turn has been helpful and several team members believe that it has encouraged them to ask different questions of their own practice. It is hoped that this has made a helpful contribution to the development of professional expertise within the team.</p> <p>copies of the report can be downloaded at http://www.uclan.ac.uk/facs/health/nursing/research/groups/children/index.htm</p> <p>The aim of this project is to train residents of the Halton area in some background information about the research process and oral history techniques. Oral history is the recording of people's memories. It is the living history of everyone's unique life experiences. It is a vital tool for our understanding of the recent past and it is interactive: it is shared history and a rare chance to actually talk to history face to face. Once training sessions are complete those people that feel comfortable with carrying out research will be asked to put what they have learnt into practice and start using their oral history techniques to find out what health issues have affected the lives of the people of Halton over the last 50 years.</p> <p>This 12-15 month study (flexible to allow for involvement) was commissioned by Chesterfield PCT as meaningful involvement and action research was their preferred approach. It aims to undertake a broad evaluation of the novel nurse led beds in an intermediate care facility. What to focus on has been decided by the core stakeholders i.e. staff and service users. Thus effectiveness issues and patient and carer satisfaction are key</p>
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<p>Adrienne Willis adrienne.willis@centralpct.manchester.nhs.uk</p>	<p>Accessing eye care for adults with learning disabilities</p>	<p>concerns built into the design. Methods include separate patient and carer satisfaction surveys, patient and carer interviews, staff survey and interviews, patient tracking to look at failed discharges, readmissions and how discharge processes can be improved not least to promote greater patient/carer involvement in decision-making. Softer methods requested including comments box, graffiti board and first impressions questionnaires are included. Users and staff are working in true partnership at all stages and are able to participate in as much or as little of each stage depending on their wishes. We hope to start data collection in October once final ethics approvals are gained and data collection processes have been finalised. To determine best practice in providing equality of eye care using multi-agency working of current well-established links between orthoptics, optometry and ophthalmology. Participants were questioned re current eye care and offered examinations in local clinic/home visits.</p>
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Appendix 3: Conference abstracts

PLENARY SPEAKER

Biography of Sally Crowe

Sally has worked in health for over 24 years, she is now a Director of Crowe Associates Ltd. She has extensive experience in providing consultancy, training and project management for patient and public involvement in health and social care research as well as strategic/services development. Her clients include local NHS Trusts, charities, national organisations such as Medical Research Council and National Institute for Clinical Excellence.

She currently manages the PRIME (Patients and Researchers in CFS/ME) Project, and chairs the James Lind Alliance Steering Group a national initiative that aims to bring together patient groups and clinicians in decision making about areas of uncertainty in health treatments. She is also project consultant to the National Prostate Cancer Website.

She continues to teach critical appraisal, and understanding research skills to health professionals, as well as patient and public groups.

sally@crowe-associates.co.uk <http://www.crowe-associates.co.uk>

PRESENTATION ABSTRACTS

Service user involvement in forensic mental health research commissioning

Sue Spiers, Joanna Wright

Although substantial work has been undertaken in developing methods of involving service users in research, the forensic mental health context does present a number of unique problems associated with access, the need to maintain security, confidentiality and the protection of individuals.

The UK Department of Health's Forensic Mental Health Research and Development Programme commissions research on the management of people with personality disorder or severe mental illness within settings of differing levels of security, from maximum secure hospitals to those in community settings. It also commissions work related to the mental health of prisoners.

The Programme has taken a variety of approaches to involving service users in the research process:

- Commissioning an expert paper "User Involvement in Forensic Mental Health Research and Development" by Alison Faulkner and Brigid Morris.
 - Inviting service users to sit on the Programme's Advisory Board
 - Involving service users in the peer review process including Rampton High Secure Hospital Patients Council and The Revolvers ex-prisoners service user group to involve patients from forensic settings in peer reviewing
 - Commissioning research projects which address service user involvement in forensic mental health research
-

Voluntary and Community Involvement in Research

Charie Orton & Vicky Wilkinson

The project has been developed to meet one of the key recommendations of the Halton Health Study (2004). The project will use oral history to research in depth changes in Halton over the last 50 years and how these have affected the experiences of those living here. Community involvement is pivotal to the success of such a project due to the qualitative methodology.

As such the local PCT in collaboration with Halton Voluntary Action, Health & Community Care Forum, the Patient and Public Involvement Forum and Health R&D NoW have successfully trained 20 residents to become community researchers. Training involved 3 sessions per week for 3 weeks with the topic being "An introduction to health research & oral history techniques". Session One provided a basic introduction to NHS research why and how it is done. Session Two educated the participants as to the technique of interviewing and the distinction between quantitative and qualitative research and Session Three allowed interview techniques to be practiced. Participants received £20 high street vouchers for each session attended.

So far 9 residents have signed up to become community researchers to interview residents of Halton who have lived here for between 30-50 years. They will also be involved in developing the protocol and will receive further practice and training in interviewing prior to the study commencing. Contact is maintained with residents to keep them informed of progress. A steering group also meet monthly to drive the project. The proposal is being developed and the research will commence in earnest in January 2006 having secured all approvals. The training sessions served to educate those involved but also changes peoples beliefs and attitudes towards NHS research. The training was evaluated and received a very favourable response. Problems were encountered regarding payment to attendees but this was overcome with the use of vouchers. However, that was not an ideal means to reimburse people for their efforts. To conclude though it was a worthwhile experience for all involved (trainers and trainees) and we hope to continue with the project's success as we move forward into its next stage.

The Saying Hello Project

Julia Ryan

The Saying Hello Project is a Big Lottery funded study being undertaken by a research team from the University of Salford in collaboration with development partners from Age Concern Wigan Borough. The project, which is now in its second of three years, aims to investigate the strategies employed by older people in Wigan Borough to prevent and cope with isolation and loneliness or potential loneliness. Ten volunteer older people have been recruited and trained intensively as co-researchers. The research design has been developed and finalised and the co-researchers are being prepared for carrying out fieldwork. In total, 150 in-depth insights are to be gained about people's experiences of coping with loneliness or isolation. These are to be elicited through a range of methods including one-to-one interviews, focus group interviews, written 'stories', tape recorded accounts of their experiences, whilst other options such as poetry will also be available. This project is a classic example of how members of the public have been involved fully as co-researchers working in equal partnership in all stages of a research study. Their involvement has added significantly to the quality and relevance of the study design and research processes such as recruitment, interviewing, analysis and dissemination.

User involvement in NHS research - a five year journey at the Cardiothoracic Centre in Liverpool

Norman Heritage

Our presentation will share an approach to user involvement in NHS research. We believe that user involvement in research is important at all stages in the research process. We hope that others can learn from our experiences, and use our ideas elsewhere in the NHS. We are now carrying out a piece of user led research - this will be mentioned briefly. We present a successful model for involving users in the NHS research process. Our efforts have improved research quality at the Cardiothoracic Centre in Liverpool. This talk covers a 5 year journey which began with the formation of a group 'interested' in research. Today the group is leading its own research project about rehabilitation for heart patients.

The talk will cover:

- Identifying and involving users:
How did we bring together service users with an interest in research issues?
 - Working with the organisation to establish a meaningful role:
How did the group overcome any feelings of tokenism?
 - Enabling involvement:
How did the group members get the skills to have a voice in the process?
 - Cardiac research project:
How did the project get started?
 - Benefits:
Why has it all been worthwhile?
-

Evaluation of a nurse led unit: an action research study

Tracey Williamson, Mrs Elma Cooper

This presentation describes the detailed process of designing and undertaking a study of a nurse-led intermediate care unit with meaningful user involvement from the outset. The first presenter was commissioned to undertake the evaluation of a Primary Care Trust provided, nurse consultant-led service, with a request for action research. As is good practice, user involvement was employed from that point onwards and a collaborative study between ex-patients, patient representative groups and health/social care staff was designed.

The study has involved 16 participants as co-researchers in identifying the focus of the evaluation, the research questions to be asked, methods to be used and carrying out the data collection, analysis and dissemination activities. It combines traditional research activities with development activities aimed at answering the research questions using various techniques to better reach different audiences. For example interviews are being complemented by 'first impressions' questionnaires, suggestion boxes and a graffiti board. User involvement has created a more meaningful research design that is more likely to highlight areas in need of improvement from the patients/carers' perspectives. Also changes in practice are 'owned' by those involved, leading to sustained improvements in patient care. The second presenter will share her experiences as a co-researcher.

Is Vocational Rehabilitation a Transition to Recovery?

Joanne Inman, Elizabeth McGurk, Jean Smith

This study aimed to explore the recovery experiences of service users with severe and enduring mental health problems in relation to a Vocational Rehabilitation Scheme. The Local Research Ethics Committee and The Research and Development Department of the NHS Trust granted approval for the study. Two associate researchers who were also service users were an integral part of the study throughout and this brought much validity to the study.

A qualitative research method was used: twelve service users (participants) who were working on the scheme at the time of the study were interviewed using a semi-structured interview. The data was analysed independently by each of the researchers using an inductive approach. The research group then used thinking units to organise the data and definitive themes emerged. The Vocational Rehabilitation Scheme was identified as enabling participants to move on from; passivity to activity; illness to well-being frame of reference and negative to positive thinking. It was also seen as a catalyst to change in other areas of participants' lives. Actual specific work skills proved to be the least significant transition. The study indicated that the Vocational Rehabilitation Scheme contributed to participants' recovery and may be enhanced by linking with other vocational opportunities outside the NHS.

Working with disabled parents on the development of a self-assessment toolkit to identify parenting support needs

Miranda Thurston

Considerable evidence exists to suggest that disabled parents frequently have their parenting support needs overlooked, with assumptions often being made by professionals with whom they come into contact about their capability and capacity to parent their children. This can mean that disabled parents are frequently disempowered in their interactions with professionals. Cheshire Disabilities Federation obtained funding through the Cheshire Children's Fund to carry out a research project which aimed to, firstly, explore disabled parents' views of their parenting support needs and, secondly, use this information to develop a self-assessment toolkit to help disabled parents identify their needs. A steering group comprising six disabled parents was set up, who commissioned the researcher to support the project. The steering group contributed to the research process as active participants, sharing their own experiences, as well as directing the project. In addition sixteen disabled parents (including some with mental health issues) were involved in four focus groups. The information generated from these processes was used to develop the self-assessment toolkit, which was piloted with a further sample of disabled parents.

This presentation reports on the process and outcome of the project and discusses the value of this model of working for representing disabled parents' perspectives.

POSTER ABSTRACTS

Adults with Learning Difficulties in England 2003/4

Eric Emerson

National Statistics survey of the life experiences of adults with learning difficulties in England. Face-to-face interviews with nationally representative sample of 2,898 adults with learning difficulties.

People with learning difficulties were part of the DH commissioning group and part of the consortium that carried out the survey (Lancaster University, BMRB, Central England People First). We also ran a range of consultation events with people with learning difficulties to inform the content and process of the survey.

User involvement added knowledge and expertise regarding survey content, process and dissemination.

User involvement in research-assessing the effectiveness of communication therapy in the North West (ACT NoW)

Gill Pearl

This is a randomised controlled trial and qualitative study evaluating the effectiveness and service user preferences for communication therapy after stroke.

The user group (RUG) for the project comprises people who have aphasia and/or dysarthria: there are also 2 carers.

In the feasibility study the RUG developed-

- information, recruitment and consent materials to maximise recruitment to the trial

- qualitative interviewing materials that are accessible and facilitate interviewees with communication impairments.

RUG members have also been involved recruiting ACT NoW research staff, and giving public presentations about the project.

Aphasia friendly communication facilitated the RUG processes.

Benefits of involvement-

- the materials developed are optimally accessible

- materials are enhanced by continual trialling with people who have communication difficulties

- researchers had naturally occurring contact with those whom the research is about

- the role of critical friend enhanced the training, feedback and support for other aspects of the study

- the group acts as an advocate and support for the project

- members report benefits in their communication, confidence and well-being, they value the chance to contribute to potential improvements in services

- there is an ethical imperative to involve those whom the research is about.

Infant Feeding Images Project

Cathie Melvin

Leaflets, posters, calendars and the like, promoting breastfeeding, are widely used, but there has been little work done to find out what people think of them. The purpose of this study, therefore, is to try and begin to understand something about the appeal and acceptability of the **images** used in the promotion of both breastfeeding and bottle feeding.

Focus groups will be held with pregnant women, or mothers who have had a baby in the previous 12 months, and their mothers, female relative or friend. The women will be allocated to one of 5 focus groups according to their ethnicity, age or socio-

economic status, and will be facilitated to discuss images used to influence infant feeding choices.

Two hospital volunteers were invited to become paid lay researchers on the project. Meetings have been held to plan recruitment strategies and focus group venues, to undertake and consolidate focus group training and to debrief / select the infant feeding images to be used during focus groups. It is anticipated that the lay researchers will also be involved in analysis and dissemination of the research. Their contribution to the project has facilitated access to research participants and focus group venues, hopefully enhanced the image selection process and also eased the workload.

COMENSUS (Community Engagement and Service User Support) Project : In our own words

John Coxhead; Soo Downe; Lidia Koloczek; Nat Solanki

The COMENSUS project is based the Faculty of Health at the University of Central Lancashire. The aim is to test ways in which service users and carers can become fully involved in the education of health and social care professionals. We believe service user involvement will improve the quality of student learning and will benefit the practice of the health professionals of tomorrow. The project is now two years into its three year life.

The project is being assessed through Action Research. Service user and carer involvement has increased as the work has progressed. This has been through taking part in the project advisory group and, recently, forming the Community Involvement Team (CIT). Participation has included story sharing, group interviews and membership of the co-researchers group, and collaboration with the cyclical planning and organization of the project and the research. A particular example of positive work between the project staff and the CIT was the joint preparation and presentation of a poster and a workshop at service user involvement conference in Canada.

The project is constantly changing. For example, the move from an Advisory Group to a Community Involvement Team is expected to progress further towards a Social Enterprise Firm.

The Needs and Wants of Older People from the NHS

Christine & Peter Johnstone

It is the duty of the NHS to consult with Patient and Public Information Forums (PPIs) on any alterations to the health service. I was requested to "Find the Needs and Wants" of older people from their health service.

This I did by sending out a simple questionnaire, asking what they wanted, to as many people and organisations as I could in the short time available, also requesting they did not put their names on them.

This information was sorted into various categories then typed up in the persons' own words. I drew maps of various " pathways" I felt the information received had suggested.

This work was then presented to the Chief Executive of the 3 PCTS for North Cumbria and the top clinicians at a special meeting. To heighten its profile I pasted every sheet onto a roll of wallpaper and pinned this on the wall for all to see. It has been circulated further in book form.

There was no professional input into the piece of work, just, the words of the elderly people as to their wants and needs and myself putting them into the document I presented on their behalf.

Carer Survey for Cardiac Patients and their Carers

May Griffiths, Lesley Swithenbank and Kerry Lynch

The Carer Survey for Cardiac Patients was a project undertaken in collaboration with the Cardiac Network, Social Services Carers Development Officer and a Patient and Public Involvement representative from Blackpool PCT.

May Griffiths; a patient representative had been a former carer for her husband, but like other carers was unaware of the support available when she needed it. Following her experience and through her voluntary work in the sitting service, May felt that it was important that carers receive the information and support that they needed to ensure the quality of life was maintained.

To this end a carer questionnaire was developed and distributed to 285 carers of patients with CHD in Blackpool with a very successful 42% response rate received. The results are currently being analysed, but early findings suggest that carers would like to be recognised for their expertise and as such be involved in the planning of care for their relatives.

What has this project done for you? The effect of user involvement on service users and healthcare professionals

Sue Hinder and the PND team

Health professionals in East Lancashire knew from their own experience that there was a considerable problem of postnatal depression within the Asian community. They decided to investigate the issue and recruited 9 South Asian women from the local communities to act as co-researchers. The women provided vital background information, facilitated focus groups, carried out interviews along with health professionals and assisted with the interpretation of the findings.

The project was very successful with some very important and surprising findings.

At the end of the project the research group of service users and health professionals were asked "What did this project do for you?" The answers were inspiring.

Speakeasy

Cath Sisson

Speakeasy is a peer interview initiative for Older People. Started in 2003, the project aims to explore the views of Older People from more marginalized groups through the peer interview process. The initiative gives Older People the opportunity to have a say in how services develop and helps them develop the skills and confidence to take part. We started with 12 Volunteers- all recruited from the groups we intended to target. Each Volunteer had a locally delivered 3 day training which was commissioned from the University of Wolverhampton (Centre for International Development and Training). The Centre has particular experience in empowerment and development work. The volunteers have worked on many initiatives in East Lancashire and have enabled us to gain a unique insight into the views of Older People.

The initiative is embarking on a new round of recruitment and training in March and places are available to local partners.

Appendix 4: The conference programme

Sharing Successes: Public Involvement in Health and Medical Research 3rd February 2006 Woodlands Conference Centre, Chorley

9:30am	Registration and Coffee
10:00	Welcome and introduction to the day. Sue Hinder, Chair of the North West Users Research Advisory Group
10:05	Tackling treatment uncertainty together - the James Lind Alliance. Sally Crowe, Chair of the James Lind Alliance Steering Group
10:50	Commissioning research in forensic mental health: involving service users. Sue Spiers & Joanna Wright
11:20	Coffee & networking
11:50	North West Project presentations <ul style="list-style-type: none">• Voluntary and Community Involvement in Research. Charlie Orton, Vicky Wilkinson & Lay representative• The Saying Hello Project. Julia Ryan• User involvement in NHS research - a five year journey at the Cardiothoracic Centre in Liverpool. Norman Heritage
12.35	Concurrent workshops to discuss the projects & issues raised
1:15	Lunch & poster viewing
2:00	North West project presentations <ul style="list-style-type: none">• Evaluation of a nurse led unit: an action research study. Tracey Williamson & Mrs Elma Cooper• Is Vocational Rehabilitation a Transition to Recovery? Joanne Inman, Elizabeth McGurk & Jean Smith• Working with disabled parents on the development of a self-assessment toolkit to identify parenting support needs Miranda Thurston
2.45	Concurrent workshops to discuss the projects & issues raised
3:25	Reconvene and evaluations
3.30pm	Close