Public Health Resource Unit
"Supporting Public Health"

Effectiveness and Quality in User Involvement Projects (EQUIP)

Final Report

October 2004

Authors:
Linsey Hovard
Sally Crowe
Nain Hussain

www.phru.nhs.uk

Acknowledgements

At its best, this project was about partnership. EQUIP would like to thank all those who have engaged with us in the course of the project in a spirit of sharing and learning together.

We thank the research team members who have attended workshops and events. Many of these – especially the consumer members – have done so in the context of busy schedules and complex life situations, overcoming a range of practical difficulties. They have made each session warm, fun, and productive.

We would also like to thank those people who have shared with us their objectives, reflections and enthusiasms for developing consumer involvement, and who have contributed to the planning and the delivery of workshops and outreach visits.

We thank our partners in this work – the former London Research and Development Support Directorate, INVOLVE, the 4 Ps, Sheila Hollins and St. George's Hospital Units, and latterly the Evaluation team at the Peninsula Medical School and Professor Dorothy Atkinson from the Open University.

Note on terminology

It is notoriously difficult to find a single term that aptly describes the 'lay' participants in these projects. They come to the work with a wide range of experience and represent a wide range of perspectives – for example, they may be patients, carers, service-users or members of the public. They may be working as researchers, co-researchers, panel members, advisors or user-representatives. They may or may not have previous academic experience. For the purposes of this report the term 'consumers' is used when referring to the lay participants, although we acknowledge the significant limitations of the term. The 'researchers' are those who came to the projects with a predominantly academic background and focus, though there is overlap, since some of the consumers also had previous research experience.

Distribution

This report has been prepared for our fund-holders, INVOLVE and will be made available to the evaluation team. The full report will be available to members of the eleven research teams free of charge on request.

Contents

Summary **3**

Membership of EQUIP **5**

Core principles **5**

Timeline **7**
Internal actions and changes 8

Background to the work **17**
The original proposal 17
Changes in the context of the work 18

Needs Assessments **19**
2001 19
Needs Assessment Questionnaire 19
Summary of responses 20
2002 21
2003 21
Summary of responses 21

Summary of workshops delivered **23**
2001/2002 23
2003/2004 25

Workshop style **27**
Introductory workshops 7th December and 13th February 2001 27
29th April 2002 30
17th January 2003: Listening to People – Working Together 30
5th June 2003: Whole day event 38
Workshop One: Working with specific groups 38
Workshop Two: Dissemination of research results 46
Workshop Three: Communication 48
10th December 2003: Analysis - What do the Research findings mean? 50
15th December 2003: Presentation Skills 52
16th March 2004: Sharing the Research 54
Making Things Happen 55

Workshop Evaluations **57**
2001/2002 58
2003/2004 58

Outreach Work **61**
October 2002-April 2003 61
April-June 2003 63
2003-2004 63
'Endings and closures' session 63

Reflections on Outreach **71**

Communication and Process **75**
Communication with research teams 75
Diversity 75
Access 76
Communication within the EQUIP team 77
Inclusiveness and Accessibility 78

Reflections on the EQUIP project **79**

Lessons learned **83**

Finances **87**
Summary of overall project budget and expenditure 87
Annual financial statement 87
Year One 1.8.01-31.7.02 87
Year Two 1.8.02-31.7.03 88
Year Three 1.8.03-31.7.04 88
Financial breakdown 88
1.8.02-31.7.03 88
1.8.03-31.7.04 89

References **91**

Appendices **93**
Appendix 1: Learning Needs Review Dec 2003 93
Appendix 2: Summary of Responses to Learning Needs Review - December 2003 99
Appendix 3: Project Timescales 104
Appendix 4: Attendance at Workshops 105
Appendix 5: Consumer Involvement Issues – 5th June 2003 109
Appendix 6: Evaluation Form 112

Summary

EQUIP is a collaboration of trainers with expertise in a diverse range of health-related fields, all with a 'consumer involvement' focus. In 2001 we responded to a tender from the London Regional NHS Executive to provide training to support a network of consumers and researchers in policy-making and commissioning. However, EQUIP's input was subjected to significant changes even before the first training session began. Most significantly, changes in the organisational infrastructure for Research and Development in May 2001 changed the whole focus of the project. Instead of supporting a cohesive network with a shared vision and infrastructure from the outset of the research process (commissioning), we would now be required to support eleven diverse projects already commissioned in separate Primary Care Trusts with eleven different protocols, timelines, and mechanisms for consumer involvement. In effect, circumstances shifted the focus from inviting consumers to be actively engaged throughout the research cycle, and developing their own process and models for involvement within a cohesive infrastructure, to support for separate research teams inviting involvement in individual projects.

By August 2002, after the first three workshops, it had become clear that the training EQUIP had originally proposed, based on the team's work with other networks, was not meeting the needs of this diverse group of research teams in the changed context. The training plan was therefore refined (EQUIP, Sept 2002) after consultation at a meeting with members of the projects and fund holders. The revised plan aimed to balance the needs of individual projects with the original aim of the London R&D Directorate to nurture a network for consumer involvement throughout the research cycle. Our strategy was to combine group workshops with outreach visits to individual research teams. Many of these workshops would now need to be developed from scratch. We took a facilitative approach with a strong emphasis on interaction and practical activity. Topics were agreed based on further needs assessments.

In the remaining two years EQUIP provided a programme of workshops, outreach, and remote contact with the research teams. Workshops aimed to develop

involvement of consumers throughout the Research Cycle (INVOLVE, 2001). Topics spanned the key stages of the cycle – from appraising research to analysis, dissemination and implementation. Key skills for involvement – such as communication, teamwork, and presentation skills were also covered. Our whole day event on the 5th June combined interactive workshops with a framework for sharing learning. Outreach visits were offered to all teams, but uptake was low (EQUIP, April 2003), and the potential of these sessions was realised only partially and for a small number of the research teams.

The altered context for this training required that EQUIP work with a group of projects coming from different starting points, and without a cohesive or stable infrastructure to support them as a group. This presented us with significant challenges in engaging the research teams as a group, and this report presents some of the lessons learned in the process. In a context of change, separateness and diversity that continued throughout the life of the project, the original vision of a consumer network is far from being achieved. However, we believe that – for those who engaged with the sessions - the training has contributed to increasing skills and knowledge across a wide range of topics important for consumer involvement throughout the research cycle. We hope that some of these people will continue engaging with research in the future with enhanced confidence, skills and knowledge.

Membership of EQUIP

Over the lifetime of the project the EQUIP team membership has included:

Linda Bonney	Agnes Hibbert
Jane Bradburn	Alison Hill
Elisabeth Buggins	Linsey Hovard
Cindy Carlson	Nain Hussain
Nicky Clisby	Sandy Oliver
Sally Crowe	Linda Seymour
Gillian Fletcher	Michelle Talla

This collaboration represents experience in the following fields:

- NHS Management
- Health and Social Science Research
- Experience in and an understanding of patient and public involvement in research and development
- Experience and understanding in voluntary sector working
- Health service provision and clinical NHS experience
- Experience of working with people who communicate differently

Core principles

The core principles of EQUIP are:

We recognise consumers' expertise as part of an equal partnership

We value research and lay knowledge equally

We promote sharing of skills

We aim to develop empowering relationships

We promote inclusion

Summary list of projects: number and title

18 – Can a lay-led self management programme for chronic illness improve the health of Bengalis? A randomised controlled trial with cost effectiveness analysis

35 – Promoting testicular self-examination and awareness amongst young men with learning disabilities

57 – Identifying unmet health needs in older people: the development of a valid and reliable instrument for primary care

58 – Reducing the inequalities in access to primary health care services by adults with learning disabilities by the implementation of personal health profiles

73 – Exploring the risks of falls from the perspective of older people, carers and health and social care professionals

81 – Promoting partnership – Facilitating effective primary care provision for people with communication disabilities

92 – Can screening people registering with primary care improve the detection of tuberculosis? A cluster randomised controlled trial in an East London PCT

101 – A parent-led exploration of parents' views of the child health surveillance/ health promotions programmes offered to them during their child's first year

106 – Developing young people's involvement in mental health in primary care: towards consumer produced quality standards

112 – To use the aesthetic component of the index of Orthodontic Treatment Need to measure agreement between normative and perceived orthodontic need amongst 12-14 year old children from different ethnic groups in schools in Harrow and Hillingdon

Timeline

The following shows the key events that affected the development of the EQUIP project over time.

Time	External changes	Internal actions and changes
May-Jun 2001	"Shifting the balance of power" = shift of focus of work from London Consumer Involvement Network to prospective primary care research programme.	EQUIP group re-evaluate their position and decide to stay with the changes.
Jul 2001	EQUIP and 4 P's formally renegotiate contracts to work with primary care projects. Funding decisions for primary care projects delayed until September 2001.	Delay means that no needs assessment can be undertaken over the summer as planned.
Sep 2001	Funding decided for 11 primary care projects.	Needs assessment commences despite incomplete research groups. Workshop dates postponed due to incomplete research teams.
Oct 2001	**Introductory workshop** for researchers by 4 Ps. EQUIP introduced. EQUIP to explore outreach opportunities with projects. Region decides to allocate money for Years 2 and 3 of the programme to include commissioning of research, although it is not clear at this point who will have responsibility for commissioning research.	EQUIP and 4 Ps decide to run a joint workshop in December. 4 Ps to administer these workshops (to avoid confusion).

Time	External changes	Internal actions and changes
Nov 2001	4 Ps decide not to renew their contracts for Year 2 and 3 work, but will support workshops until September 2002.	Jane Bradburn leaves EQUIP. Analysis of needs assessment helps plan the first workshop.
Dec 2001	**First joint workshop** and most projects are present for the first time. Formal offer of outreach work made.	Two teams 'de brief' their experience of working together. Sally Crowe leaves PHRU, and becomes independent member of EQUIP.
Jan 2002	Outreach pilot doesn't take off. Notification of management of project (training and support) transfers to Consumers in NHS Support Unit (CiNHSRSU). No decision about management of the primary care research projects yet.	Sally Crowe 'care takes' EQUIP until new appointment made.
Feb 2002	**Second joint workshop** First 'Bi-Annual' event hosted by Regional Executive.	EQUIP present at the biannual meeting on the challenges to the programme so far. 4 Ps not present at meeting.
Mar 2002	Broad agreement to re-negotiate the scope of the EQUIP work with CiNHSRSU in June at handover.	
Apr 2002	**Research skills workshop**, many more attendees than expected.	Nicky Clisby takes over managing EQUIP. Already project teams are changing – problems with database updates and perceived confusion in research teams about whom they are accountable to.

Time	External changes	Internal actions and changes
May 2002		EQUIP agree to re-scope the support with 4 Ps leaving and much variability in the projects.
Aug 2002	Reflection and planning meeting for EQUIP and the research projects. Action plan agreed for way forward with workshops and outreach.	
Sep 2002	18th Sept. Second Biannual meeting at London NHS R&D Directorate. 4 Ps report on their decision to leave the project.	Linsey Hovard joins PHRU with responsibility for management of EQUIP. Nain Hussain arrives as Project Officer to help with EQUIP. New workshop and outreach plan drawn up based on report of August meeting. All workshops will now be largely designed from scratch. Elisabeth Buggins and Linsey Hovard present EQUIP future plans at Biannual meeting.
Oct-Nov 2002	Telephone conferences set up with EQUIP team. Meeting with CiNHSRSU, and their new Project Officer for this work. Response to offers of outreach is mixed. A small number of projects engage. Others do not respond.	Linsey and Nain begin to get to know the EQUIP team and the other parties involved. Each research project has a named member of the EQUIP team for outreach visits and liaison, and contacts are made. Sally Crowe assists in facilitating panel meeting with Project 73

Time	External changes	Internal actions and changes
Jan 2003	Meeting with London R&D and CiNHSRSU. EQUIP learn that the London Office will no longer be providing support for the projects in the same way, and will no longer host the biannual networking meetings. Project 81 completed.	EQUIP agree to host an event that combines some of the functions of the Biannual meeting with elements of the workshop plan. The focus will be on consumer involvement. Additional funds are agreed to enable this to be a larger-scale event.
Jan 2003	**"Listening to people – working together" workshop**. EQUIP plan the event in collaboration with Margaret Flynn from St. George's Hospital. Outreach session with project 106	Workshop facilitated by Cindy Carlson and Linsey Hovard. Feedback indicates that enthusiasm for involvement is re-energised for those who attend, and the inclusiveness of the workshop is appreciated. Alison Hill works with Project 106 to discuss tools and techniques for focus group and expert panel.
Feb 2003	Margaret Flynn leaves St. George's. Margaret gives EQUIP another contact name at St. Georges.	EQUIP attempts to work with St. Georges' Unit for next workshop. Eventually find Margaret has left. Make contact with her colleague, who also leaves before the next workshop is planned.
Mar 2003	Regional R&D function ceases to exist – Biannual meetings cease.	

Time	External changes	Internal actions and changes
Apr-Jun 2003	Project structures and time-pressures make it difficult for them to accommodate visits from EQUIP. Some projects have now ended or are nearly at an end. Project Officer at INVOLVE (formerly CiNHSRSU) leaves.	Planning for the June Event. EQUIP offer to visit all projects to facilitate reflection on consumer involvement and prepare for poster / other presentations at the meeting. Tailored work on presentation skills also offered. No projects take up these offers. EQUIP supports, instead, by telephone / e-mail where research teams are responsive. A semi-structured framework is provided for the posters and presentations.
Jun 2003	EQUIP host a **networking event** with a focus on involvement. Four projects bring posters and five give presentations. Consumer partners from 5 projects present their work either formally, or as part of the plenary discussion. The event includes **three workshops** covering topics in the training plan.	Work for rest of 2003-2004 planned with input from INVOLVE and project members who are able to stay. The timescales of the projects are considered, and the group agrees that the priority is for input on presentation, dissemination and implementation ('making things happen') skills. This could include an opportunity for projects to share their work with others, and apply their learning within the session.

Time	External changes	Internal actions and changes
Jun-Sep 2003		EQUIP starts to plan for a 1-day workshop 'Sharing and applying what we have learned', to cover presentation, dissemination and implementation skills and actively involve the research teams in using these skills to share their work. Projects are notified of date and venue.
Sep 2003		Sandy Oliver and Linsey Hovard assist with the recruitment process for the external evaluation of the consumer involvement programme .
Sep 2003	Meeting with INVOLVE, including new Project Officer. Concerns expressed about the format of the proposed workshop. Project 10 completed.	Plans for a workshop on presentation, dissemination and implementation ('making things happen') skills are significantly modified following discussion with INVOLVE. EQUIP needs to re-plan. Projects are notified that workshop is postponed.
26th Sep 2003	Sharing and Applying what we've learned workshop postponed.	
Oct 2003		Nain goes on maternity leave.
Oct 2003	Sheila Hollins Unit at St Georges Hospital hold a workshop for Projects 35 and 58.	Project 58 invites Linsey Hovard. Linsey meets some people involved with the projects for the first time.

Time	External changes	Internal actions and changes
Oct-Dec 2003		EQUIP re-plans. After reviewing notes of meeting on June 5th and project timelines, work begins on new workshops on analysis, presentation, and dissemination. Projects are notified. A short Learning Needs Review questionnaire is sent to projects.
Dec 2003	**Analysis workshop.** Evaluation team member attends as participant observer.	Sandy Oliver and Linsey Hovard facilitate. Representatives from projects 57 58, and 106 attend.
Dec 2003	**Presentation Skills workshop.** Evaluation team member attends as participant observer.	Gillian Fletcher and Sally Crowe facilitate. Consumers from projects 35 and 57, and Researcher from project 73 attend.
Jan 2004	**Learning Needs Review** questionnaires returned. Research projects still running: 18; 57; 58; 73; 92; 106; 112	Priorities are 'Making Things Happen' and dissemination skills workshops. Two projects still responsive to outreach. One request for new topic – 'endings and closures' with Project 58.
Jan 2004	External evaluation of the whole programme commences (Peninsula Medical School).	

Time	External changes	Internal actions and changes
Feb 2004	**Sharing Research Findings** (dissemination skills) **workshop.**	Sandy Oliver and Linsey Hovard facilitate. Researcher from Project 112, two consumers and a consumer-researcher from Project 57 attend.
Feb-Apr 2004	EQUIP attempts to work with projects on invitation list for 'Making Things Happen' workshop. (Local commissioners, practitioners with an interest in implementing projects' research findings). No suggestions from research teams.	
Apr 2004	'Making Things Happen' workshop postponed, due to low response rate and absence of appropriate partners for sharing perspectives on this topic.	EQUIP decides to open the workshop to colleagues with an implementation / supporting role in the Trusts where the projects are based, to get the commissioners' perspective. INVOLVE is supportive.
May 2004	**"Making things happen"** (implementation skills) **workshop.**	Elisabeth Buggins and Fiona Ross (Researcher, Project 73) facilitate. Representatives from three projects signed up but were unable to attend on the day. Only project 73 is represented. Commissioners / practice developers from Trusts in London attend and express support for the projects in theory, but there is little scope for making plans to act on this interest, as few research team representatives are present at the workshop.

Time	External changes	Internal actions and changes
May-Jul 2004	Project 58 require outreach session. Meeting with INVOLVE	EQUIP prepares proposal for presentation at INVOLVE conference, November 2004. EQUIP liaise with Project 58 re. outreach session to explore 'endings and closures'. 'Debriefing' meeting, with INVOLVE, and agree function and content of final report.
Sept 2004	Outreach session with Project 58 EQUIP support project ends.	Linsey Hovard consults with Professor Dorothy Atkinson from the Open University. Linsey facilitates outreach session on 'endings and closures' with Project 58.

Background to the work

The original proposal

The EQUIP collaboration was formed in February 2001 in response to a tender from the London Regional NHS Executive. The tender invited proposals from organisations to provide training to support the development of a London-wide Network for involving consumers in NHS research and development.

EQUIP comprised members of the Public Health Resource Unit, (PHRU) and the College of Health, and individuals who had been previous partners with PHRU in patient and public involvement (PPI) projects.

The project officially commenced in April 2001. During April 2001 EQUIP were informed that they would be working in partnership with another training provider, the '4 Ps' who would support the development of PPI in research with professional groups. Despite the preference from EQUIP for a multidisciplinary training approach it was decided to see this change as an opportunity to work with another like-minded training provider and contracts were agreed.

The original proposal described the provision of two sets of workshops that addressed the training needs of lay members of a proposed 'London Consumer Involvement Network'. Learning objectives were identified, with the caveat that these would be altered in the light of a planned needs assessment exercise. They covered areas such as understanding and describing the research cycle and different research methods. Research governance, shared understandings of patient and public involvement and how to get a wider input to the involvement network would be covered. EQUIP planned to carry out a needs assessment between May and August and commence the workshop programme in September 2001. Existing evaluative tools used in previous projects would be amended for use in this project.

Changes in the context of the work

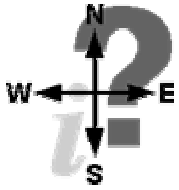
National developments were to change the context for this project drastically and in May 2001 the sweeping changes, subsequently known as “Shifting the balance of Power in the NHS” were announced. This heralded the demise of Regional Offices in their current format and many of the future R&D functions were unclear. Without Regional commissioning of R&D this project had no premise to exist. However, at this time there was a round of commissioning for primary care projects with a strong user involvement focus in process. The regional executive suggested that EQUIP and the 4 Ps could re-focus their support work on these research teams.

This posed some interesting questions for the collaboration:

1) Did we have the right skills to meet the projects’ needs?
2) Would there be enough money to provide some meaningful support to a diverse group of projects?
3) How much would our existing resources designed for commissioners of research be adaptable to primary care research project teams?

EQUIP decided to pursue the project in its new format, recognising that a sizeable amount of the project budget had already been spent developing workshops for commissioners.

Needs Assessments



2001

In 2001 it was agreed that EQUIP would co-ordinate the needs assessment exercise for researchers (on behalf of the 4 Ps) and consumers. Questionnaires were developed from previous work with the Alzheimer's Society. These were sent to all of the research leads and the research partners identified in the project bids. Where possible, telephone contact was made with consumer groups to find out whom the most appropriate person was to send the questionnaire to.

It was agreed not to pilot this tool as it had been piloted before in other projects, but it become clear that its layout and content proved inaccessible for some research partners. For two of these, subsequent telephone calls helped to clarify what their learning needs were. In retrospect this tool should have been piloted to ensure that it was as accessible as possible for a wide range of recipients.

Needs Assessment Questionnaire

Recipients	Sent	Returned
Research Leads	11	7
Consumer Partners (names taken from the proposals)	24	6

Projects that did not respond to the needs assessment exercise:

Project 18: Can a lay-led self-management programme for chronic illness improve the health of Bengalis?

Project 81: Promoting partnership - Facilitating effective primary care provision for people with communication difficulties.

Project 92: Can screening people registering with primary care improve the detection of tuberculosis?

Summary of responses

The results for the research leads were forwarded to the 4 Ps. The summary learning needs identified for consumer partners is shown below:

What do users want to learn about, and be able to do?

- To run a research workshop for potential applicants for the researcher posts on the project. Would like support for this, including help to develop content for the day.
- Facilitation skills of a group of carers/users.
- Would like training for the main functional role of the user partners, i.e. running focus groups and interview skills/techniques.
- Background to the projects.
- How is research funding decided?
- Learning about the research jargon: capacity building, governance etc.
- Approaches to research, what study for what question.
- How to encourage a democratic approach, so all are equals in the research process.
- How to access people who have different cultures.
- Increase confidence in communicating, putting ideas across, commenting on reports/proposals.
- Finding out users views and experiences.
- Getting ethical approval for research – how?
- Networking, making useful contacts.
- Presenting carers/users views to researchers.
- To know more about the project.
- How will this group change attitudes?
- How will my organisation be involved?
- How research can enhance users perspectives/feedback.
- How can users/all of us work together to make this work? & get views of users.
- Users being paid.
- Who has the power?
- Will it really make a difference and can we show it?
- To get support throughout the project (independent of research team).
- Plans. Methods of approaching users.
- Keeping optimistic.
- Helping users feel powerful.
- Learning how to teach professionals new ways of working.

2002

On 13th August 2002 EQUIP carried out a needs assessment at a meeting with research teams. The following needs were identified:

- Communication, facilitation and influencing skills.
- Skills for specific functional roles such as focus groups, meetings, and various forms of presentation.
- Enhancing consumers' skills in commenting on reports and proposals ('critical appraisal').
- Sharing stories or case studies of consumer involvement, and 'lessons learned'.
- Enhancing consumers' skills for teaching researchers new ways of working.
- Enhancing researchers' skills for discovering consumers' views and experiences.
- Disseminating good practice and implications for the future.

In addition, some needs were identified that were specific to individual projects:

- Training in qualitative research methods.
- Enhancing researchers' skills for training young people.
- Training young people in consensus methods.

2003

The final stages of training input were informed by a Learning Needs Review questionnaire in December 2003 (see Appendix 1). Telephone interviews were offered as an alternative.

Summary of responses

The full response set is shown in Appendix 2.

54 questionnaires sent out.

13 responses received, plus one telephone interview as requested = 14 responses.

26% response rate.

All projects that were still running were represented, except for Project 92 (Can screening people registering with primary care improve the detection of tuberculosis? A cluster randomised controlled trial in East London PCT).

A consumer from one completed project (81 'Promoting Partnership: Facilitating effective primary care provision for people with communication difficulties) responded.

The following priorities were identified:

- Writing research reports.
- Dissemination.
- Making things happen (implementation).

There was a preference for half-day or short day workshops, with Tuesdays suiting the largest number of respondents. Project 58 would not be able to attend Tuesday sessions.

Two projects (73 and 58) were still interested in outreach visits. Six respondents expressed interest in telephone and / or e-mail contact.

Two offers of involvement, both from researchers:

- Project 57 on "addressing the needs of minority groups".
- Project 73 on implementation.

Other needs identified: Project 58 unable to attend workshops on Tuesdays and difficulty accessing central London locations. Requested work-based (outreach) session. Need for work on 'endings'.

Summary of workshops delivered

In response to these needs assessments, EQUIP delivered the following workshops. Attendance is shown in Appendix 4 (names have been deleted).

2001/2002

Date And Venue	Structure	Topics	Numbers attending	Research teams represented
Dec 7th 2001 North London	Special event hosted by London Regional Office	Introduction to EQUIP. Nature of involvement in projects so far. Defining questions that consumers want to ask researchers. Working in project groups explore issues raised in morning.	8 consumers 12 researchers	10,18,35,57, 58,81,106
Feb 13th 2002 London	Joint working all day	Roles and responsibilities in project work. Practical issues of involvement e.g. payment of consumers.	6 consumers 8 researchers	10, 35, 57, 58,81,106
Apr 29th 2002 West London	Half-day workshop (afternoon)	Research Cycle. Research Methodologies. Action planning for areas of involvement.	5 consumers 9 researchers	10,35,57,58, 73,106

In addition, London Region hosted two biannual events.

Date and venue	Structure	Topics	Numbers attending
Feb 21st 2002 Central London	Bi Annual event, hosted by London Regional Office	Verbal updates from project staff. An update by EQUIP Q and A session about training and development issues	4 consumers. Either research lead or project officers attended from all projects
Sept. 18th 2002 Central London	Bi Annual event, hosted by London Regional Office	Update from all projects, EQUIP and 4Ps	All projects represented

Projects that were not represented at workshops in 2001-2002 were:

Project 18: Health of Bengalis.

Project 92: TB screening.

Project 101: Child health surveillance, parent's views.

Project 112: Orthodontic need in 12-14year olds.

2003/2004

Date and Venue	Structure	Topic	Numbers attending	Research teams represented
17th January 2003 West London	1-day workshop	Listening to people. Working together. (communication and teamwork).	8 consumers 4 researchers 3 helpers	10; 35; 57; 58; 73
5th June 2003 Central London	Whole-day comprising: 1 -2 hour workshops integrated with networking and presentations from the project teams to share learning. Structured posters on 'what works well' and 'top tips'.	Working with specific groups (raising issues of culture and communication in teams). Dissemination (targeting audiences. Role of consumers). Communication. (adapted from 17th January workshop).	7 consumers 7 researchers	35; 57; 58; 73; 106
10th December 2003 Euston, North London	Half day workshop (afternoon)	Analysis: What do the research data mean? (Introduction to analysis. Role of consumers and multi-disciplinary teams).	5 consumers 1 researcher	57; 58; 106
15th December 2003 North London	Half day workshop (morning)	Presentation skills. (Practical session, tips for presentation).	2 consumers 1 researcher	35; 57; 73

Date and venue	Structure	Topic	Numbers attending	Research teams represented
16th March 2004	Short day workshop (10.30 – 3.30)	Sharing research findings (dissemination and writing/ presenting as a team).	3 consumers / consumer rep. 1 researcher	57; 112
26th May (postponed from 6th April)	Short day (10am-4pm).	Making things happen. (Implementing research findings).	2 researchers 1 panel member 4 London com-missioners.	73
September 2004 Project 58.	Outreach visit: Facilitated session.	Endings and closures.	3 researchers 9 consumers	58

Workshop style

EQUIP workshops were set up so that the project teams could all learn from one another about consumer involvement, even though the projects are all different. We welcomed all members of the research teams, regardless of their previous experience and background: We believe that people who have an academic research background and those who do not can all learn from one another.

We used an interactive style that aimed to respond to the issues raised by participants. We used facilitation techniques and aimed to foster learning through practical activities (experience), interaction and reflection. Workshops drew on adult learning theories, incorporating elements of problem-based learning, action learning, reflective practice and some direct knowledge-teaching. Where possible we aimed to use (and we always sought) scenarios and issues given to us by participants. New materials and exercises were developed for the majority of these workshops, and some of them are described here.

Introductory workshops 7th December and 13th February 2001

These sessions were run jointly with the 4 P's organisation. EQUIP worked with the consumer representatives, whilst the 4 Ps worked with the researchers.

Issues covered in the workshop included:

- Defining and discussing 'what is a user'.
- Whom or what do users represent? What does it mean to represent?
- The need for clarity about the roles, responsibilities, and time required of consumers in the projects.
- What it means to feel respected / disrespected as a user
- Issues of ethics and payment when employing users on projects.
- Power relationships
- Communication and the use of jargon

- Roles of the various partners in the project (London Regional Office, 4 P's, EQUIP, external evaluation)

Care was given to ensure that all participants, particularly consumer partners had the time and space to get to know each other, reflect on 'their' projects so far and identify practical issues between the group.

The afternoon sessions concentrated on group discussions around some of the issues in an effort to find ways forward.

The facilitators were asked to collate questions for the research teams and Region. In the first workshop these were addressed in the after lunch session in the second workshop they were described to researchers at the regional bi-annual event.

The sorts of issues that were identified included:

- Appreciate a definition of 'What is a user?' (Researcher new in post)
  Very basic details of the users' roles within their projects have still not been resolved.
- Areas of confusion exist around roles and responsibilities, as well as payment for time.
- Time, people had been asked to be involved but were given no indication of how much time would be required, or how much time specific tasks would take. For example form filling could take anything up to several hours for a person with learning disabilities.
- People felt there was a fundamental disrespect, i.e. that as users they had all the time in the world. There was no sense that they had made a choice to participate, and nothing about the 'opportunity cost' element of people choosing to be involved in the project rather than something else. One user summed it up when she commented 'I could be playing bridge, or looking after my grandchildren'.
- Representativeness of users, "Am I meant to be representative of all users from my group, or just give my views as a user from that particular group?'

- Language used in research teams, e.g. ‘capacity building’. It was suggested that researchers should not be using jargon in their dealings with user members of the teams.
- Power relationships that researchers would never give up their power or take users seriously unless they too could use and understand the jargon. (Experienced user)
- There is a need for some sort of written agreement between users and their projects so everyone is clear.
- Type of language used, one person didn't like the term 'user' at all because for her it sounded like a drug user. She felt more comfortable with the term 'co-researcher'.
- Payment is an enormous issue. People gave examples of being told prior to their involvement that they would be paid 'x' amount and then it never materialised. People's travel expenses were not being reimbursed.
- The training days with EQUIP and the 4Ps had never been budgeted into projects because there was no clarity from Region about what the time commitment would be.
- How should project teams’ feedback/evaluate their work for LRO? They suggest they keep a team diary of chronological events or develop their own evaluation method, any ideas from LRO on what they are expecting?
- Will there be an external evaluation of all the projects? E.g. the Outcomes for Socail Care for Adults (OSCA) project had external evaluation, any such initiative should focus on the process outcomes as well.
- It would have been helpful if 4Ps & EQUIP could have played more of a supportive/monitoring role during the lifespan of the projects, as many need help and supervision.
- How important is user involvement really in this programme, especially to the senior project team members? What are professionals learning about user involvement to make it real and not tokenistic?
- Have users themselves been involved in deciding on the evaluation measures, and most importantly, what difference do LRO think that user involvement will make to the projects? What are they looking for?

- More info/guidelines please on thorny issues such as ethics of employing users and ensuring they are not used inappropriately. The users' gains and role in the projects should be clarified please or at least more help achieving individual project guidelines.

Some of these issues could be dealt with in a workshop format, but many of them relate to areas that the two teams are not funded or charged to do.

29th April 2002

This half day session consisted of three main strands:

- What is the research cycle?
- Different types of research.
  This looked briefly at a Randomised Controlled Trial, qualitative method and a cohort method.
- A chance to look at how consumers might influence the research methods of a project. Issues around inviting patients and consumers to participate.

The practical group activity based on Research Cycle has been used by the Public Health Resource Unit in a wide range of contexts, to stimulate thinking about the roles of consumers throughout the process. In small groups, participants 'arrange' the elements of the cycle into a logical sequence, discussing the role that consumers might take at each stage. In our experience, this is a useful activity for stimulating concepts of consumer roles, and we have found that consumers who do this activity across time, extend the scope across which they can identify a clear role for themselves.

17th January 2003: Listening to People – Working Together

Facilitated by: Linsey Hovard and Cindy Carlson

This session consisted of practical activities to highlight issues in communication and teamwork. We worked closely with the collaborative research team at St. George's Hospital Medical School Department of Psychiatry, who did some preparatory

work with people with learning disabilities who wished to attend the workshop. They also made suggestions for modifying activities, though in the event little modification was needed as the participants had been so well-prepared. Feedback from participants and the facilitators' own observations indicated that this event was successful in terms of its 'inclusiveness'.

The workshop aimed to develop participants' understanding of the role communication and teamwork in achieving more effective consumer involvement.

Specific objectives were to:

- Explore participants' perceptions of what working together means to them and how people work together effectively.
- Identify what gets in the way of their ideal picture of working together and explore *why* these barriers exist.
- Identify communication and facilitation strategies for making the most of what everyone has to contribute, and for keeping everyone involved throughout the research process.
- Set their own objectives for building on their existing practices for working together, whatever the current stage of the project.

Participants were asked to draw and/or discuss their ideal vision of involvement. We then discussed barriers and facilitators, which were represented on a 'wall', with a 'ladder' (cardboard cut-outs) made up of post-it notes produced by the group.

This led to the 'Communication Bridge' activity. The group worked in two teams, with the task of building half a bridge each, in separate rooms. At intervals throughout the task, each team sent out a representative(s) to communicate for one minute with the other team. The objective is to build two identical halves of the bridge.

In the afternoon, we moved on to consider communication in groups and teams. Participants were asked to negotiate a decision in a role-played team meeting. Some were given specific roles or 'challenging behaviours' (for example, 'someone

who constantly criticises other people's ideas', someone who continually draws attention to his own single-issue).

These activities, whilst carried out with much zest and hilarity, generated some sharp perceptions, as the flipchart summaries show:

Flipchart Summary – Successful Research Project

BARRIERS	SOLUTIONS
• Misunderstanding • Service Users not understanding project	Users involved at design stage
Jargon & technicalities	Make project info accessible
• Controlling – not sharing or including • Unequal responsibilities • Tokenism • Rhetoric	Make participants feel valued – and remember that what you learn as you go along, is as important as the end result.
• Not believing • Lacking confidence to participate • Lack of belief in us (service users)	Valuing contributions at meetings
Loss of personnel/ key individuals	Team building
• Lack of clarity about user role. • People lose interest.	Show respect – provide assistance. Encouragement, recognition of conflict, communication.
• Fear of lack of power (researchers and service users) • 'Chemistry'	Trust – openness is key.
Lack of expertise/ training (researchers and service users)	Honesty about roles
Not understanding the project	• Willingness to share information. • Willingness to listen.

Flipchart Summary - Communication

The task is to construct a symmetrical bridge from duplo across a river.

Teams are located in separate rooms. Each team must construct half the bridge and the two halves must be identical. Each team has exactly the same number and type of bricks. The bridge should span the river and the teams will be commended for the sturdiness and attractiveness of the bridge.

The only communication between the two teams will be a one-minute meeting between one member of each team, after every five minutes. During this one-minute, the nominated 'communicators' will leave their teams and will speak outside with the other person. They can use a flipchart and pen but they cannot bring any notes or bricks with them to this meeting.

The group completed the task, producing an interesting structure!
The key points we discussed in the feedback are outlined below, and our quote of the day was:

"Half an argument (like half a bridge) is no good!"

"Strong, broad foundations"
The base of the bridge was very important, just as the basis of a research project should be solid in terms of aims, objectives, methodology, finance, staffing, etc.

"Simple construction"
It's easy to over-complicate.

"Language"

People needed to be clear in their descriptions of the individual components and the overall structure. It helped if people used similar terminology as far as possible.

"Roles"

One team chose to send the same person out each time as 'communicator' – the other team sent different people. There was discussion about whether it was best to allocate a role and maintain continuity, or whether different people brought different skills. On balance, it was agreed that continuity was preferable.

"Compromise or flexibility?"

The teams reached a point where they decided one team should design, and the other should 'follow instructions' so that the two halves of the bridge would match and meet. The group agreed that this was a sensible method but were clear that the 'following' role was not adopted because one team was 'weaker'. It felt sensible to allow one team to take the 'lead' as this was the best way to achieve the task effectively and in the given time. The team which were leading should not be seen as winners or more important.

"Time"

When time is limited it helps if you are clear, concise, and if possible have planned what questions you need to ask, and what information you need to give.

"Methods"

Within the two teams there were different ideas about crucial ways of building. This was because there were a variety of ideas, knowledge and understanding within the team. The team had a very limited time to resolve the differences and collate the information they wanted to share with the other team. It helped to have a constant reminder of the task and aim.

"Congratulations!"

Self praise and self-belief helped to motivate, and see the value of the process as well as the outcome.

"Getting the message across"

The two teams started to use drawings as the activity progressed – and agreed that these made it easier to convey the key information. Using a range of methods of communication can be very helpful.

"Competition"

It's not about winning….but the group did admit that there was a competitive spirit, which at times could be helpful, but at other times was a hindrance. It was important to feel that the teams were working to the same end aim, and on **one** project not two.

"Assumptions"

Where communication was lacking, both groups had to guess or make assumptions. This was inevitable but could cause difficulties and confusion.

"Priorities"

The two priorities in forming this bridge were to **produce a sturdy structure** and **keep the design simple** so that it was easier to describe it to others.

Flipchart Summary Three - Working with Groups

This activity took the form of role-playing a steering group meeting. The scenario was that the research team had realised that they were unlikely to have enough money to cover all the activities they were contracted to carry out. They had decided that the only option available was to stop paying transport and participation fees to users and co-researchers on the project. In this meeting, two representatives who are chairing the meeting have to inform the group of their decision and get them on board. Other participants in the meeting were asked to

role-play various characteristics including, very positive, critical, very quiet, hostile, focussed on one-issue…..

The role-play was acted out with gusto! In the discussions which followed, the following issues were raised:

1. Observations of the meeting:

- When asked to comment, some people never have anything positive to say.
- Negative interactions were more dominant than the positive.
- Criticism was coming primarily from one area.
- Not everyone was given an opportunity to express their views.
- Being quiet is not the same as agreeing.
- Personal reasons come into play.

2. Suggestions for a more successful meeting:

- Remember that service users should be at the centre of the project.
- Give support – be flexible, aim to meet individual support needs.
- Think about how you communicate.
- User-friendly language.
- If things are getting difficult, take a break – this might give people a chance to calm down - or if someone is being particularly unreasonable, or has issues which are not relevant to the meeting, they can be taken aside to see if the matter can be addressed.
- It can be hard to achieve the balance between 'getting the job done' by announcing a decision that has effectively been made and engaging/ interacting. One way of reducing this difficulty may be to ensure that the person tasked with delivering the (bad) news does not also have the role of chairing the meeting – they should be part of the main group which will help facilitate discussion. The Chair should have a neutral and separate role.
- Keep people on track. It's OK, if the issue is not relevant, to say that we can discuss it later. Acknowledge the issues and link with others who might help.

- Establish ground rules - how to treat others, how we wish to be treated - for the meeting, as we did for the workshop. Bring people back to them if necessary.
- Send an agenda in advance.
- Remember that agreement needs to be reached in the meeting – this is the aim/ target. Keep it in your sights.
- Use body language if need be. If one person is dominating, you are likely to be looking at them more and more. Make a conscious effort to direct your attention in another direction in the room.
- Pick up on positive/ constructive points.
- Remember hostile arguments may well contain legitimate points!
- Use specific questions which might promote inclusion e.g. “we’ve got some service users here. What do you think?”
- Ask questions/ find out what people think, before ‘telling’ them what has ‘been decided’ – but in reality there is often no choice and the decision has been taken before the meeting. Or ***is*** there, in-fact, **always** a choice, if you’re sincere about functioning as a group?
- In reality, people do change roles, within the space of one meeting and from one meeting to the next.
- Always look for constructive solutions.

5th June 2003: Whole day event

This event comprised three two-hour workshops. There was also a plenary session, in which project representatives gave presentations and invited discussion on the consumer involvement aspects of their projects. The project teams, that attended, prepared posters about their work and gave us their 'top tips' for consumer involvement. Appendix 5 shows the themes emerging from the contributions.

Workshop One: Working with specific groups

Facilitated by: Linsey Hovard and Sally Crowe

Objective of session:

- Think about the role of culture and communication in different groups
- Explore examples of adapting to cultural differences
- Consider the communication needs of different groups
- Work out some principles for working with specific groups

How we worked:

We discussed what makes groups 'special'. Two of the key factors were **communication** and **culture**. The group worked together, and at times in two smaller groups, to share their understanding of communication and culture. In focussing on culture, two groups worked with a specific scenario (asking the Bank Manager for a loan) and drew parallels with the experience of their research project. The group also produced a 'spider gram' about key communication issues and how to communicate effectively. We then summarised the ideas and information generated by the group.

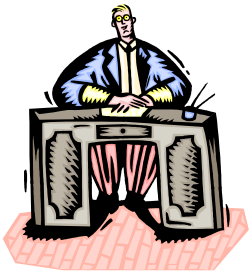
What is Culture?

The scenario….

You have to go and see your Bank Manager to persuade him to lend you some money. Think about the way they do things at the bank. How is it different from the way you usually do things? How do you feel? Would it be different if you asked your Bank Manager round to tea to discuss it?

This is what people at the workshop said:

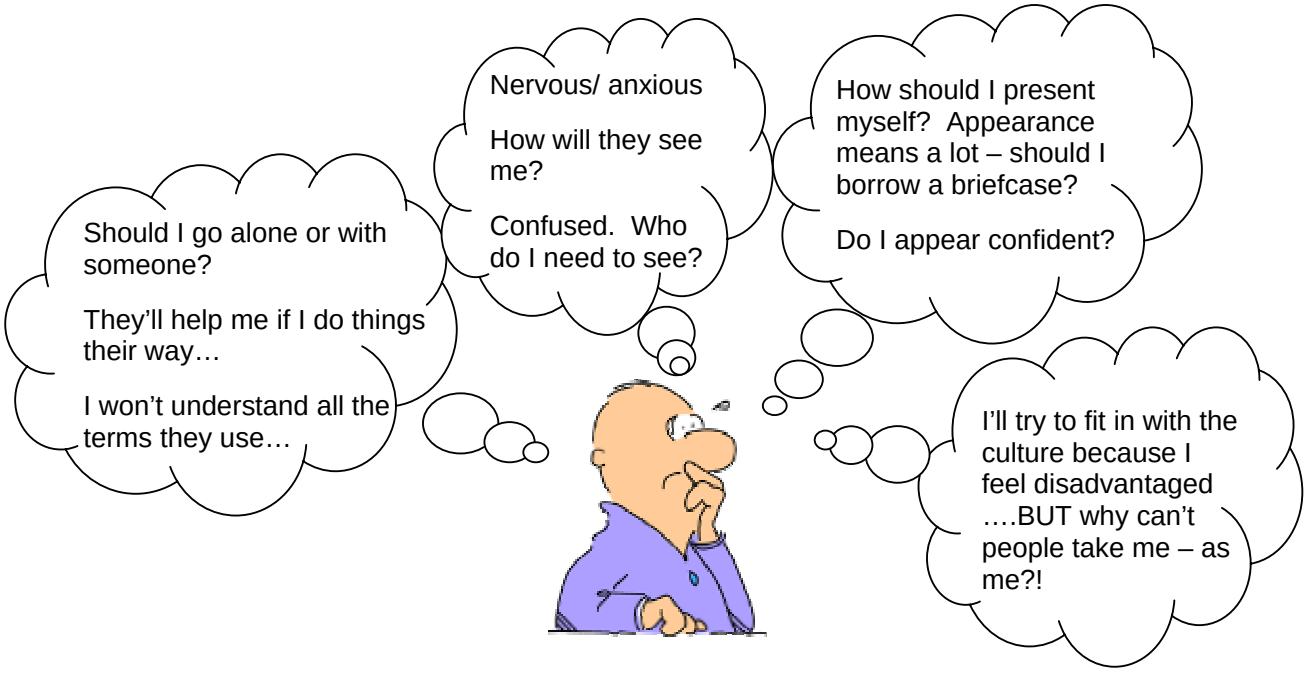
Bank 'culture':



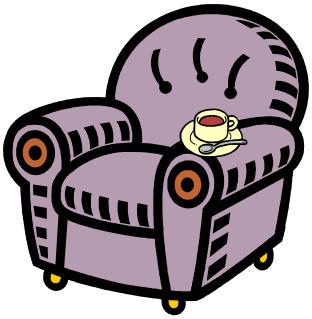
- Money and status (how 'important' they think you are).
- Your status may be judged very superficially.
- The bank's agenda is to make money, not to 'help' people.
- There are 'rules'.

But we know not all banks are the same (even if in some ways they look the same). Some know their customers well and consider their needs and their comfort.

How do you feel when you visit the Bank Manager and ask for a loan?



….And what if you had the Bank Manager round to tea?



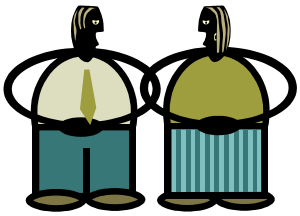
- I'd feel better because I'd be on my own territory.
- I'd tidy up.
- We'd each have a nice comfy chair.
- I'd get out my best china and posh biscuits.
- I'd feel happier….but I'd still need to impress.

So what did we learn from imagining ourselves in this situation of asking the Bank Manager to lend us some money?

On the whole we imagined we would 'bend' to the way the bank does things. Theirs is the dominant culture and they hold the power.

But we, the less dominant culture, will not give of our best, and the Bank will not get our business unless the Bank Manager understands and accommodates our needs too.

When we looked at how we might do things differently if the Bank Manager came to tea with us, we started to see some signs of cultures moving towards each other and a slightly more comfortable relationship for the customer. To us, it didn't seem that these were big changes, but for a culture which is used to doing things a certain way, they might seem too difficult or awkward.



Cultures must work together and move towards one another to meet at a fair point otherwise everyone loses out.

One participant saw a parallel between the way people are treated by the bank and the experience of some patients in the NHS, "Inverse Care Law". This means that in accessing the bank and the NHS those who are most in need often find it most difficult to find their way around the system.

Workshop participants made these key points:

Try hard….and remember the simple things….

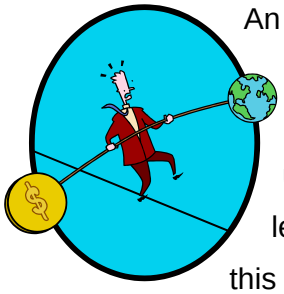
- Sometimes you (professionals and others) have to be prepared to go to the limit to get results!
- Workshop participants appreciated that it's hard to deal with complexity when you're busy.
- Some projects did manage to make the necessary changes to involve consumers fully – but it meant that they couldn't do everything they wanted to do. Re-think how much you can get done in a meeting.

- Simple things can make a big difference. Some workshop participants felt that services would not always make enough time for people with learning disabilities for example, even though simply finding a suitable pace and a little flexibility (e.g. around appointments) would enable them to participate.

Knowledge:

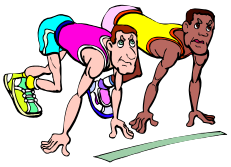
- Users of the service are not seen as having the knowledge that can be helpful.
- Consumers need a level of expertise just to find their way round some of the complex systems that exist in health services and research. Even when they have very little help they often manage to gain this expertise and can do so in any area with the right support.

Finding a balance:



An issue that professionals faced was the balance between making sure that they were giving the same information and detail to everyone versus concern for an individual's understanding. This isn't only applicable to people with learning disabilities – in any piece of work involving real people this tension exists. The workshop participants felt that this tension was still unresolved at the highest power levels.

Process:



- Consumers should be involved from the very beginning of a project to ensure that the project allows the time needed and can make adaptations to process. However funding rarely commences from the planning stages and this can create difficulties.
- The consumer can have a key role in obtaining consent from individuals to participate in the research study. However, this is something which often happens at the early stages of a project, before consumers are involved. Also, if the researcher is seen to be the expert on the project, they are often seen as the person best placed to explain and seek consent, when actually a consumer could be helpful in devising the wording, protocol etc to obtain consent.

Honesty:

- Openness can achieve so much more!
- Some of the most important words an expert can say are "I don't know…."

Working with Specific Groups: Communication

What aspects of communication do we need to consider when we work with specific groups?

Make it simple for *everyone!*

Language

- Get a consumer's point of view on the language – or ask them to write the information and consent sheets. Reach an agreement on wording.
- Change the terminology if necessary, or explain the terminology used if it can't be changed.
- Find the time, resources and expertise to put things into symbols and other suitable formats.
- Speaking can be more useful than written minutes, reports – or can at least complement these.

- Professionals sometimes use jargon without understanding it fully themselves. Everyone benefits from keeping the language as simple as possible.

Be sensitive….but not too scared to ask….

- Be aware of sensitive issues, images and language.
- Tell people in advance what you're working on and that these subject are likely to be raised.
  e.g. Stereotyped ideas about older people, sex and relationships.

  Approaching the subject of death (and finding a multicultural image of death).

  Mental health – some people consider there is a stigma attached to this and may be reluctant to discuss their experience – consider the words and labels they find acceptable.

Seek clarity

- Don't make assumptions about what other people think.
- Think about the language you use - words can be so muddily, e.g. sick/ terminally ill.
- Avoid too much subtlety or innuendo!

Time is money?

- The funding culture – the Bank Manager scenario has echoes here! How do you persuade him to come to tea with you?
- The trend for shorter, cheaper projects – can this be at the expense of good practice of equal opportunities? – Need for proper resources for involvement.

Share the learning

- Make sure that the consumer involvement in your project is really seen to be more than words. Include it fully in the research paper, talk about the

consumer involvement side when you write it up and present it. Be honest about it.

- Communicate with other teams, e.g. within the Primary Care Projects network. Try to set up an informal 'peer-review' system.

We asked people to tell us about communication in their research projects

The PROP project:

The older people's panel are very busy people with a range of other commitments. They have come together to do a job. Communication is core to ensuring that they function effectively as a group.

Some of the important elements are:

- Social element – friendship
- Cohesion
- Fun
- Respect
- Dealing with conflict – healthily
- The group have shared background information, about their past work, interests and motivation to join this project.
- At the beginning of the project, aims were drawn up. Reminders of these aims are given at meetings. Meetings can sometimes be quite far apart and the reminders help to get people 'back into' the project and 're-orientating' to where the project is.
- Newsletters are also produced and help to keep people informed between meetings.
- Technical aids to communication were also required – microphones, hearing loop.
- Visual reminders of need.
- Also, simple techniques – photos of the group, scanned photos of the group were used in Christmas cards – a nice friendly touch and a helpful reminder.

Aphasia Project:

Like the PROP project, this project found that good preparation and investment of time created a group which communicated well.

- Getting to know the group helped to make communication more effective.
- Bigger print, pictures, gaps between lines of words all helped.
- Made the time to work out how to write the minutes of meetings in a way that everyone could understand.
- Found that Aphasic people were able to help explain things to people with learning disabilities – they could spot when the understanding wasn't there.
- The group benefited from having a facilitator who could prompt the group to establish ground rules and reach group agreement.
- The **process** of working out how to conduct the research project and meetings helped contribute to the project **outcomes**.

Unmet Health Needs Project:

This was a different kind of project and the committee had a more formal feel. The difficulties were partially acknowledged with the appointment of a 'link' person between consumers and medical professionals.

Joining the committee was daunting at first:

- The Doctors used a lot of jargon.
- It was hard to keep up with the technical discussions. Required more explanation/ definition and could sometimes feel awkward asking for this.
- Consumer members can feel 'outnumbered'.
- Can they (the professionals/ the system) change?
- No 'social' feel to the group. Quite formal.
- This group has, uniquely, appointed a 'Consumer Co-ordinator' who's role is to act as a link between the professionals, researchers and the co-researchers.

Workshop Two: Dissemination of research results

Facilitated by: Alison Hill and Sandy Oliver

Objective of session:

Knowing how to share your research findings effectively.

How we worked:

We worked in two small groups to discuss opportunities for disseminating research results. Each group was asked to put the results of their discussion on to hexagon shaped post-it notes so we could draw out some themes from the groups' discussions. Participants arranged and rearranged their post-its on the wall to group themes. These are set out as key tips for projects.

Planning dissemination:

- Start planning well in advance of the end of the project.
- Involve users and consumers in the planning.
- Design the project outcomes to ensure that they are accessible to users and consumers.
- Plan to inform all stakeholders about the outcomes of the project.

Clarifying key findings:

- Be clear about what you have found out.
- Make sense of the information and know who needs to know about it.
- Find out what is important to consumers.
- Involve users and consumers in prioritising findings.
- Be clear on what to say and what you think they need to know.
- Share the positives with your team.

Identifying the stakeholders:

- Know who you need to reach.
- Make sure decision makers are informed and primed to act.
- Be clear about message and then target appropriate audience.
- Disseminate to as wide an audience as possible.
- Make sure that the users and consumers involved in project know.

Identifying the ways and means of disseminating:

- Get to know your networks and information points.
- Find imaginative ways to get consumers involved in the dissemination – working to strengths.
- Involve users in planning the type of formats.
- Use the overview and scrutiny process in local authority.
- Engage the users in the approaching of the overview and scrutiny committee.
- Find funding and sponsorship from care organisations.
- Gain the commitment of key organisations.
- See if local media schools and drama schools could help in production.

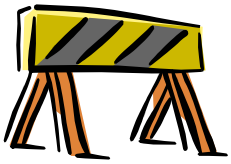
Communicating the research findings:

We identified a variety of ways that the research findings can be communicated and disseminated:

- Videos
- Newsletters
- Web
- Talks and presentations
- Flyers, posters
- Drama productions
- Video with vignettes (in training) (for boards)
- DIPEX Database of Individual Patient Experience
- Academic paper
- NHS research database.

Barriers to disseminating results:

- Knowing how, and having the skills, to share information.
- Finding the time.
- Preparing for possible rejection (the long haul).
- Knowing what you are going to say (specific content), i.e. to specific audience.
- Using the 'right' keywords and concepts.

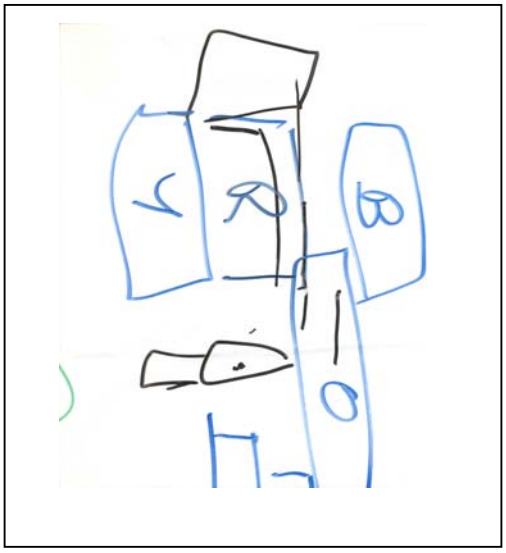


Workshop Three: Communication

Facilitated by: Elisabeth Buggins and Cindy Carlson

Elisabeth and Cindy facilitated a shortened version of the 'Communication Bridge' activity described above (see page 31). Even in its shortened form, much learning took place.

The following picture is the output from the two 1 minute communication meetings:



Lessons learned (from flipchart):

- We built a pretty bridge!
- Discussion between parties should have taken place first, before building began
- Questions arose as to who should lead the process? Or should both adapt?
- Communication needs to be two way
- Clarification is key to taking the project forward
- Balance of time for talk and the task is important
- Need to be clear about roles and expectations
- Visual medium communicates ideas faster than words
- The product being 'good enough' is okay
- Having a more flexible timetable is necessary
- Can delegate power but not responsibility (e.g. role of principle researcher)

As one of the team's communicators was aphasic she relied particularly on visual communication. Everyone agreed that this had been a benefit to communicating with each other, as relying on words alone would have been difficult.

10th December 2003: Analysis - What do the Research findings mean?

Facilitated by: Linsey Hovard and Sandy Oliver

This workshop aimed to give participants an insight into the wide range of ways of approaching data and to explore the value and ways of involving consumers in the analysis process.

In our first main practical activity, groups of three participants sorted and described a bowl of mixed sweets and pasta. The responses and ensuing discussion demonstrated the wide variation in ways of analysing information. Interestingly, as the flipchart record shows, one group took a more qualitative approach, whilst the other group focused on counting and categorising:

Group A	Group B
Sweets or pasta	32 sweets → Wrapped 5; Unwrapped 24 114 pasta pieces **Dolly mixture** 5 Purple 10 orange 2 brown 5 → 1 purple 3 orange 1 pink 2 other
Hard or soft	
Different colours	
Wrapped or unwrapped	
Ready to eat or needed to cook	
Chocolate appealed more than dolly mixtures	b) red 7 → spiral 6, bow 1 green 18 → spiral 13, bow 5 normal 89 → spiral 8, bow 6 75 ladders

We drew on this introductory discussion as participants listened to a brief tape-recording, and were asked to identify significant themes. They then considered a health questionnaire, and discussed how they might aggregate and categorise the findings in order to draw out significant findings and relationships in the data. Finally, we used a scenario to prompt discussion of the importance of ensuring the analysis 'fits' with what you are trying to find out from the data:

Scenario to prompt discussion of outcomes

Day care for pre-school children away from their own homes is a regular topic in the national press. Some writers focus on how day care varies in different areas, and how poorer families find it difficult to get their children into good quality day care. Other writers focus on the value of children being looked after by their own mothers.

> *What do you think might be the benefits or harms of day care for pre-school children? If day care for pre-school children were to be evaluated, what should be used to measure its successes or failures?*

The group considered a range of outcomes and measures that could be used, and voted on them, illustrating that different members of the group prioritised different outcomes for analysis. We then used two rounds of 'votes' to identify consensus in the potential outcomes.

Finally, we discussed the advantages and disadvantages of involving consumers in analysis. Responses were varied, but most participants felt it was important for their perspective to be included during the analysis phase of the project:

- We bring things back to basics
- We learn from each other
- We ask different questions
- Too technical for us to make an impact
- A role in the questionnaire (for a particular project)
- Part of the discussion
- What have we found out so far?

15th December 2003: Presentation Skills

Facilitated by: Sally Crowe and Gillian Fletcher

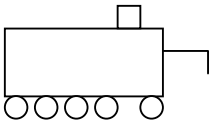
Learning Objectives

This session aimed:

- to explore what makes a presentation really memorable and inspiring
- to help participants identify their 'presentation needs'
- to enable participants to practice presentation skills in a safe and relaxed atmosphere

Participants were asked to identify their own key objectives for presentations. After an illuminating (and fun) demonstration of effective and ineffective presentations, they had the opportunity to try out their own presentation skills, focussing on their own specific targets. A range of suitable 'props' was provided. Flipchart notes from the session illustrate the issues that were raised in this workshop:

Flipchart Notes - What would I like to do better?

- Anxiety about "experts"
  - "tongue tied
- dealing with questions – going blank
- 'power of passion'
-  Pacing
- Courage – allow it to change while its' happening – "going with the guts"
- Style "Richard and Judy"
- Being a bit more factual
- Adapting the style to the audience?
- Making it more visual different
- Balance between being responsive and losing track

Flipchart Notes - Boring and Uninspiring Presentations - traps to avoid

- Information overload
- Not providing what the audience needs or will find interesting
- No connection with the audience (smile, relaxed stance, make eye contact)
- Boring / monotone (pauses / timing)
- Disorganisation

Flipchart Notes - Effective Presentations

- Dress to suit
- Make eye contact
- Challenge status quo
- Through audiences eyes + belief
- Enthusiasm & Commitment
- Know what you're talking about
- Engage – dialogue
- Clear potential benefits
- Visuals support, not crutch. Humour
- ? Stand up / sit down
- Frame presentation – end with recommendation

16th March 2004: Sharing the Research

Facilitated by: Sandy Oliver and Linsey Hovard

In this workshop, participants were encouraged to formulate the messages that they considered most important to disseminate and to identify their main target audiences. They compared a range of different types of publication, and considered the types of publication that their own target audience would be most likely to read.

We incorporated discussion of the structure of the NHS, to prompt exploration of forums in the NHS that might be used for dissemination, paying particular attention to the avenues for patient and public involvement. We then worked on a framework to identify the key messages, audiences, and appropriate forums for dissemination. Finally, participants began to plan the content of their presentation or writing. Dissemination avenues that participants identified for their own projects included outreach visits to schools, formal presentation for a Professional Executive Committee meeting, and writing for GP Bulletin.

26th May 2004: Making Things Happen

Facilitated by: Elisabeth Buggins and Fiona Ross

This workshop sought to bring together members of the research teams with people who have a role in commissioning services and service developments. The aim was to explore together:

- How patients and the public can be involved in influencing health service decision-making.
- How to engage local commissioners and providers in planning how to use research.

The session began with an explanation of the context for consumer involvement in the eleven Primary Care projects for the commissioners present. In small groups, participants than discussed the nature of change, highlighting barriers and facilitators with reference to projects they had been involved with. There was frank and open discussion about the pressures and motivations that influence those who make decisions about services:

Flipchart notes - Drivers for change

External:

Targets, performance monitoring, star ratings

Guidelines, National Service Frameworks, NICE

Personal:

Financial reimbursement

Self-motivation

Self interest / championing advancement

Professional:
Royal Colleges
User-led demands and expectations
Policy
Patient and Public Involvement framework
Research and development, technology developments
Local politics, sensitivities

The group then went on to discuss the range of avenues through which consumers can get involved in health service decision-making. However, it was noted that there is little formal support to enable consumers to find their way through these structures:

Flipchart notes - Avenues for consumer involvement
Patient and Public Involvement leads / Patient Advice and Liaison Service
Patient and Public Involvement Forums
Patient Survey
Overview and Scrutiny Committees
Best Value Reviews
Improvement Collaboratives
Maternity Services Liaison Committees
Health Improvement Plans
Healthy Living Centres
Foundation Trusts
Board Meetings / Public Meetings
Consultations

As the session concluded, the service decision-makers present expressed support for the eleven primary care projects and for initiatives that have involved consumers in research.

Workshop Evaluations

Although a full external evaluation has been commissioned, EQUIP has continuously sought feedback from participants and facilitators in order to inform ongoing planning.

In August 2001 EQUIP outlined the following proposal for evaluating the training:

What?	How?	Who?
1. The process of the training.	Immediate feedback and debrief at end of training.	Participants and trainers
2. The impact of the training on participants.	Pre and post workshop questionnaires.	Participants
3. Identifying the gaps in the training project.	Post workshop questionnaire. Trainer focus group or interview.	Participants Trainers
4. Identifying what is effective and cost effective.	Trainer focus group or interview.	Trainers
5. The suitability of the practical and domestic aspects of the training.	Post workshop questionnaire.	Participants

A sample feedback questionnaire is shown in Appendix 6. It contributes to evaluation of items 1, 2, and 5. The focus group to assess needs (August 2002), and the Learning Needs Review (Dec. 2003) are reported in Section 3 above. They contribute to evaluation of item 3. In addition, EQUIP has continuously reflected in our telephone conferences and e-mail exchanges on the 'fit' of the learning models we have used, and this will be the subject of our presentation at the INVOLVE conference in November 2004.

The following issues were identified in feedback questionnaires from workshop participants and trainers:

2001/2002

- Satisfaction with the research cycle exercise. Felt they had learned a considerable amount.
- Too late for understanding research methods. Want information relevant to their own project's design and issues.
- One person did want an overview of methods.
- Wanted good examples / case studies of user-involvement.
- Confusion over who was administering the programme.
- The initial venues were unsuitable for some consumer partners.
- Central London locations with good public transport access were seen as important changes to make, although access was difficult for one of the more 'outlying' projects that included people with learning difficulties.
- The workshops ran on a short day (10-4) some found this helpful. Others would prefer a half-day approach.
- Mixed responses to joint and separate training in 2001/2002. Some felt that it produced more interesting and useful discussion, others felt that it marginalized some of the consumer partners.
- Time spent in the mornings 'checking in' was helpful.
- Frustrations with the lack of continuity for participants as new people join workshops (as they are recruited to project teams).
- In joint sessions there was still too much jargon and NHS/Research speak.
- Some people dominated sessions.
- People feeling confused about what they were there to learn.
- Very different levels of understanding and knowledge.

2003/2004

A quantitative rating scale was used for some aspects of the workshops. A rating of 1 equates to 'extremely satisfied' and 5 represents 'extremely dissatisfied'. All workshops were rated at 1 or 2 for content, presentation, and overall satisfaction. Relevance and venue were rated between 1 and 3.

Themes from the qualitative evaluations are:

Facilitation style:

'The way in which the facilitators engaged with participants and enabled them to interact'

Feeling of camaraderie engendered in the groups:

'The feeling of unity'

'Friendly atmosphere and ease in expressing one's ideas'

'Feel part of a team'

Opportunity for focus and reflection:

'A chance to reflect on consumer-involvement aspects'

Mutual learning enabled by the group:

'Mix of backgrounds of the participants helped to 'stretch' the context of the topic and make cross boundary connections'.

Mixed views about the group size and make-up:

'We needed . . . more people from a wider range of projects'

'The small number of participants made the workshop extremely helpful in developing ideas from all who attended'

Lack of time and depth:

'More time for discussions'

'I felt that we only 'scraped' the surface'.

Request for greater user involvement in delivery of the workshops:

'Some user involvement would have brought about a more concentrated focus on the user experience'.

Content / relevance issues: Mixed responses

'Would it be possible to use real results from UK research as a basis of discussion'?

'Great examples and structure'

Importance of acting on new insights:

' . . . think we had a good think different things people say and do. See if it will come good.

Outreach Work

October 2002-April 2003

Feedback during workshops and the needs assessment on 13th August 2002 revealed a perceived need from many of the research teams for training that was specific to their own local needs. This feedback seemed to highlight the differences between the original vision for developing a network from scratch, and the new situation in which the eleven projects did not perceive themselves as a 'network'. This was in contrast with the original brief, and with our own objective of facilitating learning through sharing the common issues and good practice in consumer involvement.

We were not resourced to provide support separately to the eleven projects. However, we recognised that these projects had all come to the programme from different starting points, and at this stage they did not perceive joint workshops with other teams as a priority. We decided to supplement the workshops with 'outreach', in response to the request for tailored input. In 2002-2003 all projects were allocated an EQUIP team member as an outreach 'link'.

We re-allocated our resources to offer up to two visits per research team, and EQUIP made intensive efforts to contact the Principal Investigators and/or consumer representatives for whom we had contact details. The initial visits would be exploratory, with an emphasis on building relationships, identifying learning needs and understanding how best we could contribute.

The response to these initial offers of outreach was mixed. Several projects commented on the difficulties of accommodating a visit from EQUIP into busy schedules. Project 81 was nearing completion and declined the offer of a meeting. Project 92 did not respond to our efforts to make contact. For projects 10, 18, 35, 101 and 112, communication was by telephone or 'incidental' meeting only.

In the event, EQUIP team members were able to make outreach visits to projects 57, 58, 73 (two visits), and 106. Most of this work was achieved by joining the projects in existing forums.

Project 57: Identifying unmet health needs in older people.

Sally Crowe attended a consensus workshop, where she was able to offer suggestions for bringing consumers' perspectives even more to the fore, to enhance equality in the session. Sally also met with two of the consumer participants, and maintained this contact to identify how they would like to further develop their engagement in the project. This was fed back to project leads.

Project 58: Reducing the inequalities in access to primary health care services by adults with learning disabilities by the implementation of personal health profiles.

Linsey Hovard met with one of the consumer-researchers on this project. This highlighted some specific training and information needs. Linsey fed these back during a Steering Group meeting and invited the team to pursue them further with outreach from EQUIP. Linsey also initiated a brief discussion about consumers' support needs during the steering group meeting.

Project 73: Exploring the risk of falls from the perspective of older people, carers and health and social care professionals.

Sally Crowe attended a panel meeting. Sally facilitated an exercise to identify ongoing training and support needs with the consumer members of the panel. She attended a second panel meeting as co-facilitator.

Project 106: Developing young peoples' involvement in mental health in primary care: Towards consumer produced quality standards.

This team wanted to run training sessions for their youth expert panel on focus groups, facilitation and interview skills. Alison Hill met with a member of the research team to assist in planning the training session. Alison provided some resources that the EQUIP team have used in training for these functions.

April-June 2003

All projects were offered a further visit prior to the June 2003 whole day event to be hosted by EQUIP. Concerned that the initial attempts to arrange exploratory visits had lacked focus, we offered to provide support for sharing good practice in preparation for the 5th June. This could include facilitated reflection on the consumer-involvement issues, based on a framework that we had provided, and tailored support for 'presentation skills'. Each EQUIP 'link' attempted to contact the research teams to discuss outreach. No projects took up this offer.

2003-2004

In our subsequent workshops – and in discussions preparing for the workshops – we urged the research teams to consider outreach as a way of preparing for, or following up on, the workshop learning. This was not taken up. However, in the learning needs review, December 2003, two projects identified specific topics for which they required outreach support. These were:

> **Project 73** (Falls in older people) – Dissemination skills
>
> **Project 58** (Personal Health Profiles for people with learning disabilities) - Facilitation of 'endings and closures' as the project nears completion.

EQUIP began to negotiate these sessions with the project teams in January 2004. Ultimately, the visit to Project 73 was not pursued, as the timing was not right, and EQUIP offered a group workshop on this topic at a central venue instead.

'Endings and closures' session

The final outreach session to Project 58 was planned in collaboration with the research team, especially Vicky Turk and Sukhinder Burrha. Their request had been prompted by Professor Dorothy Atkinson's work on this topic. Linsey Hovard facilitated the session, which was based around the framework of building a 'team certificate'. Ten people attended. The research team utilised the framework to provide a further session on the same topic with a second group later in the week.

Objectives:

- To reflect on experiences and celebrate achievements in the project
- To identify (and describe to others) the key skills that have been gained
- To consider the impact of change on team members
- To identify support needs for moving on

Session summary:

Consumer members presented the project and their roles to Linsey and Dorothy, who were relative 'strangers' to the work. Small groups then reflected on their experiences:

The best thing we did in this project was. . .

- Teams – seeing it come together
- Working in a new area (learning disability)
- Having ideas
- Going to new areas (places)
- Finding out about the project
- Supported by team
- Being on a project that's helping people who need the PHP
- Finding out how the PHP helps people
- Helping the researchers with the questions
- When people tell us funny things during interviews
- Sharing health problems and ideas with other carers (people in a similar situation
- Giving ideas

- Meeting people
- Getting out of the house
- Having a routine
- Hearing funny things that people say
- Employing users as paid researchers
- 'Made me more assertive – confident about going back to work'
- Seeing people get more confident

The most scary thing we did was . . .

- Finding way around – worried about getting lost
- The size of the task – wondering how we would complete the project
- Explaining consent in a new way
- Visiting some estates
- People leaving – wondering if they will be okay, wondering if we will manage without them
- Feeling awkward about certain topics
- Knowing what to do when someone talks too much
- Organising childcare

Based on this, we discussed the skills that the team had gained along the way:

- Organisation & budget
- Employing users and carers
- Dealing with sensitive issues
- Being creative – getting ideas across
- Listening & explaining
    - Consent
    - People with different disabilities
    - Improving signing
- Working as a team
- Working in peoples homes and different parts of society
- Confident interviewing people

- Confident going to see people no matter what disability – you have seen it before
- Signing, communicating with different people
- Working as an equal team
- 'He has a strength when I haven't'

After lunch, we discussed ways of celebrating achievements and ways of remembering or keeping in touch. We took a team photograph, and prioritised achievements for the team certificate:

In the final part of this session, we discussed hopes and fears, and began to identify some of the ways that the team could be supported as the project nears completion:

Hopes and fears:

- Looking forward
  "If you leave something, the next thing you go on to is going to be just as good"
- Feeling of completion
  "You've folded something up and got something out at the end of it"
- Taking a chance – you might end up somewhere good.
- Wanting to know the outcome – what happens to the PHP
- Miss using the new skills we have gained
- Worried it will all fold.
- How to use new skills? - Research? A job? A course?
- Beginning to think about other things to do – e.g. courses.

Support as we move on:

Power of networks -

- Exchange e-mails / newsletter /phone numbers:
- To keep updated on progress with the PHP
- To keep in touch with each other
- Information from the team about opportunities to get involved in other projects

Continuing to support the development of the PHP:

- Telling people about our experiences in this project e.g. INVOLVE
- Get involved in telling people about this project – e.g. help with presentations.

Individual support for personal development:

- One-to-one meeting with line manager, a team member or peer, to look at own achievements, hopes and fears in more detail.
- Bexley Two-fold (local organisation supporting people with learning difficulties).

Ways of celebrating and recording achievements:

- Certificate / Personal profile / C.V.
- Party
- Team Photograph
- Evening out

Thematic Summary of Session Evaluation

Participants were asked: What did you find most useful about today? What would you have liked to have done differently?

Reflecting on achievements and the 'ups and downs' of the project:

- 'Made me realise that we had all achieved something where I would not have considered that I had – thank you'.
- 'The discussion of what we were most scared of and what we feel we done best was really useful – opened up a very good discussion amongst the team and helped us to think about these in detail'.
- Telling about our happy thoughts.

Thinking about the future:

- Made me think more positively about what we have done and more clearly about after the project ends – i.e. that we will be able to know the 'end result'.
- (Would have liked) More time to focus on future steps.

The certificate and team photograph were useful outputs:

- ''A photograph of the group will be a really nice memento'.
- 'Certificate a good idea'.

Timing:

- Good balance either side of lunch.
- Would have liked more time to go through individual plans.

Reflections on Outreach

Our outreach initiative was prompted by the realisation (after the needs assessment in August 2003) that the research teams perceived a need for support tailored to their separate projects as priority over working with the other projects. We anticipated that we might achieve wider engagement if we focussed more on the separate needs, using these sessions to identify common ground and then bringing this to the wider group (or supporting the teams to do so). Consequently we were initially surprised when we had only very limited success with our attempts to engage with the teams to negotiate our contribution. We now conclude that the challenges we faced in outreach reflect the lack of cohesion in the wider context of this project (See 'Lessons Learned', below).

Where we did achieve success, our input was in response to a specific request or invitation from the research team – usually via the Principle Investigator or someone in a co-ordinating role. It took two forms:

1. Support on a specific topic requested by the team leader.
2. Facilitation of increased consumer involvement during a session planned and set up within the project's existing framework.

Specific limitations on what we could achieve with outreach visits included:

We lacked an agreed 'permission' or point of entry to the research teams.
The management of the training (by INVOLVE) and the research projects (by the Department of Health) was separated in 2003, so that there was no single co-ordinating body to broker access or facilitate a cohesive 'buy in' to the outreach process (or the training in general).

Our access to individuals within the teams was limited.
We are aware that there are many individuals who would have welcomed external support for their involvement at the level of their project team. However, without the support of the Principal Investigators (or someone with a role in co-ordinating the teams), we did not have an 'entry point' for addressing these issues at team level. In such cases we became - in a very limited way - mediators or mentors. To

gain the necessary support from the team leaders would have required strong engagement with the programme objectives and process from the outset, as well as acknowledgement that there may be unrecognised needs within their team that would benefit from external facilitation.

Gaining support and engagement was a lengthy process, requiring time and resources from all parties.

In the absence of a shared initial vision and agreed process for access to the projects, it took time to build relationships and trust, and in most cases we did not get beyond telephone contact. In practical terms, the project teams who engaged with outreach had to allocate time to negotiate session plans and make practical arrangements that were often very complex. Significantly, some of the most substantive contributions were made only towards the end of the programme.

Potential links between outreach and the workshops were only partially realised.

Even in our limited contact with the research projects, it was clear that there were numerous examples of good practice to be shared, and that the teams were highly motivated to share their own experiences with others. We attempted to facilitate this by:

- offering support and a framework to prepare projects to present their consumer involvement work via posters, 'top tips', and presentations at the event on 5th June 2003
- encouraging teams to use outreach visits to prepare for and /or follow up on issues raised in the workshops
- fostering a shared learning approach in workshops
- working with a research team member to co-facilitate the session on 'Making Things Happen'.

Had we successfully engaged with the research teams earlier and more widely, a more focussed cascade approach might have been productive. This might entail:

- EQUIP supporting project teams to facilitate sessions on specific methods or issues. EQUIP co-ordinating these sessions with regular assessment of

the needs of the wider group of projects. This model was used in the 'Making Things Happen' session.

- EQUIP facilitating learning and development on 'project-specific' issues. Then supporting the project to bring the learning to the wider group. This might have worked well with the 'Endings and Closures' session, with Project 58.

Communication and Process

Communication with research teams

Communication with research teams was complex. Key challenges for EQUIP were:

1. The diversity within the teams – both in terms of communication preferences, and in terms of project activity and internal (to the projects) communication mechanisms.
2. Access to the teams and to individuals within the teams.

Diversity

Members of the project teams have differing communication needs and preferences. When EQUIP was aware of specific preferences, we aimed to meet them – for example, we routinely telephoned some people to follow up on written flyers or e-mail communications.

For workshops, we sent out advance notices and booking forms, followed by more detailed programmes for our events. We aimed to 'pace' information, and to strike a balance between giving enough information and making it concise and accessible.

Reports were sent to project teams with an option for discussion on the telephone or in person if preferred.

In the final year of the project, with fewer research teams involved, and a closer knowledge of the people in the teams, our process was to follow up all workshop flyers with telephone calls and e-mail. We then telephoned again all those who expressed interest in a workshop, to discuss their objectives for the session informally. We also used these telephone discussions to attempt to involve potential participants in the planning, to make workshops more relevant. For example, in preparation for the analysis workshop, we asked research teams if they would be willing to provide some anonymysed data samples for use in the workshop. Whilst one project responded positively, this team member was unable to attend on the day, and in the event we used pre-prepared data. For the

dissemination workshop, we asked those who had signed up what types of dissemination activity they anticipated. Thus, we attempted to tailor the content of the workshops to the individuals who would be attending. In the event, however, these were often not the same people who attended on the day.

There was also diversity in the research teams' internal communication processes and models for partnership. We attempted to arrange outreach visits to fit in with the diverse organisational structures of each research team. For example, we attended steering groups and consumer panel meetings where we were invited. This did place some limits on how well we were able to connect with the teams, and especially the consumers / co-researchers who were working with the projects. Ultimately, our communication depended on how well we were able to get to know project members through their attendance at workshops, and attending their meetings where we could.

Access

Access to individuals in the research teams was challenging. EQUIP's starting point was a list of individuals named in the research proposals. They were asked to disseminate our information in their teams. In 2002 this list was updated after contacting project leads. However, our database remained incomplete – we would meet new people at workshops and events whom we were not previously aware of. Thus in some instances the process relied on project leads to disseminate our notices and information to those who were not on our list. One project lead requested that all information go through the Principal Investigator.

For some projects, knowing who might benefit from the training was not clear-cut. We received telephone calls from organisations that had received our information, but were uncertain whether they were directly involved with one of the eleven research projects (for example, a consumer group holding a general 'advisory' role for researchers in their field, who had had some contact with the project). Through the course of the work, we gradually met people who were involved with the projects, and whom we had not previously been aware of.

Outreach contacts identified needs for support at both individual and team levels – and at the interface between the two. We are aware that there are people who would have welcomed outreach visits to support their involvement in their team activities. However, without the support of someone with a role in co-ordinating these teams, our role was limited. On occasions we became 'go-betweens', attempting to feedback sensitively on issues that consumers had raised.

Arranging outreach visits during existing research team meetings placed limits on whom we could meet. For example, in one project consumer-researchers worked in two teams, on two different days, with representation on the steering group on a different day. All of the teams had highly-pressured schedules, and immediate tasks to perform, which made it more difficult for them to accommodate us.

In some instances it was not possible to arrange a visit to a research team, and there was no opportunity for EQUIP to directly meet the consumers involved.

Communication within the EQUIP team

The EQUIP team itself is diverse – both geographically and in terms of areas of expertise. Our aim was to bring to each workshop the team member who had most to contribute to the topic, and the diversity in the team was beneficial in enabling us to cover topics that span involvement throughout the research cycle. Our process was to negotiate facilitators, dates and times of workshops at telephone conferences. Research teams were notified of the date and asked to reply to express interest (In the final year, we made telephone calls / sent e-mails to all our contacts to follow up on the flyer). The EQUIP facilitators would then plan workshops in outline. Staff at the Public Health Resource Unit would follow-up the flyers with e-mail and telephone calls, to refine our understanding of what participants might want from the workshop. This was fed into the facilitators' plans, and objectives for the workshops were then sent out.

Telephone conferences were invariably stimulating and creative sessions, in which we discussed our plans, reflected on our process, and generated new ideas for subsequent stages of the programme.

Inclusiveness and Accessibility

We aimed to ensure that all our workshops were meaningful for people with different abilities, experiences and interests. We contacted research teams who showed an interest in attending a workshop, so that we could identify any additional requirements. Our facilitative approach aimed to enable participants to voice their preferences and have them supported.

Our administrator, Linda Bonney referred to Mencap and The British Dyslexia Association websites, and abstracts from the Royal National Institute for the blind 'See it Right' Pack for guidance on making our information accessible. We offered to talk people through our reports and information if they preferred this method of communication.

Reflections on the EQUIP project

This project began with a vision of developing a cohesive network for consumer-involvement in research in the London Region. However, changes in the external context – and particularly the re-organisation that occurred with 'Shifting the Balance of Power', challenged this vision. Rather than developing together from the outset, our task became one of attempting to support a group of projects who did not see themselves as part of a network, but as separate teams with diverse needs, different timescales and different, already established models for involvement.

EQUIP combined outreach, individual communication and group workshops. We hoped that this would be an effective means of meeting the needs and harnessing the potential of individuals, separate projects, and the 'team' of projects. We hoped that it would also be cost-effective, by addressing issues with several research teams in the workshops, whilst supporting carry-over and building relationships through the outreach. However, in practice, external events meant that the outreach took off too late in the project to enable strong relationships to be built. By the time outreach was offered, the teams had already formed. They had established their diverse infrastructures, and any external influence was difficult to bring in.

Workshops require a critical mass of potential participants from which to draw. The projects had different timescales, and some were already drawing to a close by the time our training plans were refined (Sept. 2002) in response to changes in the external context. We attempted to 'match' our input to the timeframes of projects, and the budget was allocated in uneven amounts to reflect this. However, in the second year we were challenged to re-engage with the research teams after the changes in our plan. In our own presentation on 5th June 2003, we reflected that whilst we had not been successful in engaging all of the projects in the work, those that did attend were beginning to express a sense of team and cohesion. We attempted to maintain the momentum of the June meeting by planning a workshop in September, based on feedback during the June event, and

with an emphasis on sharing good practice and facilitation by project team members.

Following discussions with INVOLVE, the workshop planned for September was postponed and the plans modified towards very small-group workshops with increased communication to enable us to tailor events to participants.

From the outset, EQUIP's preferred approach was to facilitate sharing of perspectives in workshops for 'researchers' and 'consumers' together. In the first year, we were asked to focus on the 'consumers' whilst the 4 Ps would focus on 'researchers' needs. Subsequently, after the 4 Ps left, an expectation of separate needs had been set and it is possible that EQUIP was seen as having little to offer the 'researchers'. In our view, this was a missed opportunity for mutual learning and communication.

When workshops did achieve a mixed attendance, the benefits were invariably warmly received and commented on. In several instances 'consumers' who attended felt that the workshop would have been more productive had their academic partners been there to reflect on their involvement processes.
Our observations support this: In our workshops it was clear that participants frequently gained new insights into how they might have enhanced involvement in their research teams. Without the presence in the workshops of their other team members they were limited in the extent to which they could share these new understandings and put them into practice for their projects.

In a recent e-mail discussion we reflected again on our approach, and the challenges we have faced in engaging the research teams and providing relevant and timely input in a context of change and diversity. Two approaches that might have had potential for supporting a group of projects such as this came to the fore in that discussion:

1. *Intensive outreach from the outset* with individual research teams to build relationships, gain and strengthen access and mutual understanding. *Followed by* group sessions, perhaps with one or two other teams at a

similar stage or with similar needs, and perhaps facilitated by research teams with specific experiences in the topics concerned.

2. Action Learning Sets *established at the outset* of the project, with clear 'pathways', timeframes and learning objectives set by participants. Negotiation with the research teams of the values and aims underpinning shared learning ('researchers' and 'consumers' learning together). This model could incorporate some specific sessions facilitated by research team members and EQUIP, supporting with facilitation/presentation skills and identification of external experts where required.

In both models, our overarching conclusion is that training needs to be set within a strong and stable infrastructure that supports and enables collaborative working.

Lessons learned

The external evaluation will be valuable in extracting the detailed lessons to be learned from this project. In the meantime, we have drawn the following conclusions, many of which reiterate oft-cited principles of collaborative development:

1. Shared ownership; early collaboration. In a project of this complexity and diversity the parties involved need to collaborate *from the outset* to establish a set of common values, understandings, objectives and principles for working. The original vision was to do just that – the trainers were to work together with consumers and researchers to establish and develop common principles for involvement from the outset of the research, and before the research proposals were submitted. In the event, we were required to work with eleven different research teams, and numerous partners, all coming from different starting points and with separate management arrangements. The project was initiated and carried out in a climate of 'separateness' rather than cohesion: Separate infrastructures, models, values, timescales and learning needs not only for the eleven projects, but for the trainers, the fund-holders, those overseeing the research teams, the evaluators and the many partners who have contributed.

2. Infrastructure. The infrastructure for a programme such as this should support cohesion and collaboration. In this programme, changes in the external context meant that from August 2003 the training was managed (by INVOLVE) separately from the management of the research teams, and the many partners that we worked with were also managed separately. This limited the 'leverage' we had in gaining the support of the team leaders and access to the project teams, or in working with partners in a unified and consistent way.

3. Values. In this field, there is still a long way to go in establishing and describing shared sets of *values* for involvement. Our approach aimed to foster sharing of *multiple perspectives* - researchers and consumers working together, to identify how each could contribute to maximum effect. For some of the parties involved, this was a step too far - they called for separate training for researchers

and consumers. For others, it did not go far enough - they called for *integration of perspectives*. One consumer described this as a situation in which consumers could do as good a job as researchers when it comes to research task, and researchers could do as good a job as consumers when it comes to working with consumers.

4. Models. Those commissioning training should endeavour to ensure that there is a shared understanding of the teaching and learning *models* to be used. This needs to be developed early and collaboratively, and should be a good 'fit' with the shared aims of the whole programme. In this case the collaborative learning that was proposed was not universally perceived as meeting the needs of the research teams, who did not see themselves as a unified group. The facilitative style of our sessions - whilst understood and appreciated by many who attended our workshops - was not universally accepted. For some, there was a perception that this model drew too heavily on the projects themselves, rather than bringing in external expertise at a high level - the 'external expert' model.

5. Ownership and involvement. In several cases, members of research teams expressed a motivation to 'present' their work to others. Whilst we endeavoured to engage the teams in sharing their diverse skills and experiences in workshops and preparation for workshops, alternative models might have enabled greater involvement and ownership. Our planned session on 'Sharing and applying what we've learned' had aimed to support the teams to share their work within the 'sessional' framework that we had adopted. A more developmental approach (such as Action Learning Sets) might have provided a more appropriate framework for this.

6. Resources. Where a process has been collaboratively agreed, it should be supported with the resources and time for all parties to engage fully. In this project, many of the research teams cited lack of resources as their primary difficulty in engaging with the training.

7. Supporting individuals. Openness to the concerns of each individual, and good team facilitation helps to ensure that their issues are supported when there is input to the team. External facilitation can reveal new insights and promote openness. In this programme, we are aware of individuals who would have welcomed further input from an external source, but this need was not fully recognised by their teams. We provided some limited individual support, but were not resourced to pursue this in-depth. Mentoring and peer support approaches may have merit here.

8. Alignment of separate objectives with a common goal. In a situation such as this, where the parties come from different starting points, it may help first to address the separate team concerns and issues, and to gradually highlight commonalities before the benefits of collaborative learning can be perceived. However, there needs to be an appropriate infrastructure to support this.

9. Consistency and stability. Projects thrive best in a stable context, particularly in their 'overarching' infrastructures. The context and support for this project was subject to continual change and re-direction.

10. Pace and momentum. There needs to be fast response to identified needs. In this programme momentum was lost when workshops were cancelled due to low numbers or feedback from partners.

11. Multiple (or integrated) perspectives. Feedback to date supports our view that consumers and researchers have much to learn from one another, and multiple perspectives need to be shared in learning events such as these. Once again, this can only occur where there is opportunity *at the outset* for mutual negotiation and communication of boundaries, values and priorities.

12. Framework and Timetables. The Research Cycle provided a logical framework for the training. The interactive exercises and materials developed for these sessions have been well received by those who attended, and are a resource for future work in this area. However, a flexible approach is needed to enable teams to access learning on each topic at the time that is right for them.

The workshop format requires a ‘critical mass’ of participants with needs in the same area at a given time. Therefore, other, more flexible modes of delivery (such as action learning sets or outreach and mentoring - with processes agreed at the outset) might be considered for networks or groups of research teams at a single-region level.

Finances

The budget for EQUIP was £30,000 in the first year (1.8.01-1.8.02) and £80,000 for the remaining two years. The London Regional Office provided an additional £10,000 in the second year to support an enhanced event on 5th June, in place of the biannual meetings that had previously been hosted by them. The £80,000 was allocated in two parts: £60,000 for 2002-2003, and £20,000 for 2003-2004.

London Regional Office (LRO) was responsible for funding from 1.8.01-31.7.02. From 1.8.02 CiNHSRSU (Consumers in NHS Research Support Unit - later re-named INVOLVE) took over this responsibility.

Summary of overall project budget and expenditure

Year	Budget	Total Expenditure
1.8.01-1.8.02	£30,000	£31,392
1.8.02-1.8.03	£70,000 (£60,000 plus £10,000 supplement for 5th June)	£56,430
1.8.03-1.8.04	£20,000	£33,135
Total 1.8.01-1.8.04	**£120,000**	**£120, 957**

Annual financial statement

Year One 1.8.01-31.7.02

Budget: £30,000

Expenditure: £31,392.90

Year Two 1.8.02-31.7.03

Budget:	£60,000
Budget supplement for 5th June:	£10,000
Total Budget:	£70,000
Expenditure:	£56,430.80
Budget surplus carried forward:	£13,570

Year Three 1.8.03-31.7.04

Budget:	£20,000
Surplus brought forward:	£13,570
Expenditure:	£33,135

Financial breakdown

1.8.02-31.7.03

Item	**Cost**
Needs Assessment	£3,400
Outreach	£3,156
Workshops, 17th January, 5th June	£10,636
Training planning and co-ordination	£22,680
Administration	£8,700
Travel	£1,750
Reports x 3	£5,810
Stationery, printing and postage	£298
Total Expenditure	**£56,430**

1.8.03-31.7.04

Item	Cost
Learning needs review	£2,285
Outreach	£2,370
Workshops	£8,800
Training planning and co-ordination	£10,380
Administration	£7,200
Final report	£2,600
Total Expenditure	**£33,635**

References

The following unpublished reports have been previously submitted to INVOLVE. They are available from the Public Health Resource Unit on request. There is a small charge to cover administrative and printing costs. Please e-mail linsey.hovard@phru.nhs.uk.

EQUIP, August 2002
An Interim Report for the year 2001-2002

EQUIP, October 2002
Refinement of a Training Plan

EQUIP, April 2003
Interim Report

EQUIP, August 2003:
A report about a workshop for eleven primary care research projects. 5th June 2003 at Regents College, London.

EQUIP, November 2003
Year Two Report: 1.8.02-1.8.03

Further Resources

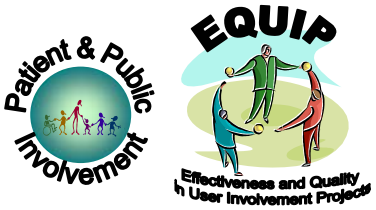
INVOLVE, 2001
Getting Involved in Research - a Guide for Consumers

Public Health Resource Unit: Learning and Development Programme 2004
Describes a range of workshops and learning support programmes to support learning close to where people work. These include Critical Appraisal Skills workshops, Patient and Public Involvement workshops, Action Learning Sets, Facilitation Skills, and Mentoring schemes. Contact: regina.lally@phru.nhs.uk

Hollins, S., Adeline, P., Bunning, K., Flynn, M., Perez, W. Towell, D., Turk, V., Wilson, J. 2004
User involvement in the London primary care and intellectual disability research programme.
Presented at the International Association for the Scientific Study of Intellectual Disability. World Congress 2004
(Available from Professor Sheila Hollins, Department of Mental Health, St. George's Hospital Medical School. S.Hollins@sghms.ac.uk

Appendices

Appendix 1: Learning Needs Review Dec 2003



Learning & Development
Public Health Resource Unit

NHS

EQUIP: Learning Needs Review

EQUIP is funded until 1.8.04 to provide training and support to the eleven Primary Care Research Projects. To help us tailor our input to your needs, we would be grateful if you would take a few minutes to answer these questions.

Please return in the Freepost addressed envelope by **6th January 2004.**

Section 1 — Workshop Topics

1a) EQUIP is funded to provide between two and four new workshops between January and August 2004.

Below you will find some suggested topics, based on feedback some of you gave us at our previous workshops, together with our own ideas. Please think about what your project will be doing, and tick the topics that would interest you in the next 8 months:

- ❑ Writing research reports that will be read by people who do not have a research background.
- ❑ Writing research reports: Skills for research teams writing together, or for consumers who are writing reports.
- ❑ Letting people know about our work (dissemination). A more in-depth look at the issues raised in our workshop on 5th June.
- ❑ Making things happen: Influencing people to put research into practice
- ❑ Models of consumer involvement in research: Exploring how consumer-involvement is organised in different projects.
- ❑ Writing new research proposals with consumer-involvement in mind
- ❑ Half-day discussion group on whatever's important to people who sign up for the workshop.
- ❑ Other (please describe any other skills or topics that you would like the workshops to cover).

……

1b) Which topics do you want most of all? (please name up to two).

……

……

Section 2 — Structure of workshops

2a) What type of training would you prefer?

- ❑ Half-day workshop on one topic.
- ❑ Whole day, covering two or more related topics.
- ❑ 'Drop-in' day, with a few sessions happening at the same time. You choose which ones you come to.
- ❑ Don't mind.

2b) Do you have any other ideas about how we could run the workshops?

……

……

Section 3 — Timing of workshops

Are there any days of the week that you **cannot** attend:

……

Are there any times of day when you **cannot** attend:

……

Which days and times are best for you:

……

Section 4 — Your involvement in the workshops

Are there any topics that you would like to lead a session on?

For example, something that has gone well, or something about consumer-involvement that you have found especially interesting?

……

……

……

What would you like EQUIP to do, to help you lead a session?

……

……

……

Section 5 — Support for Putting Learning into Practice

6a) Please describe how you have tried to use the things you've learned about in the workshops?

……

……

6b) Please describe any successes

……

……

6c) Please describe any challenges

……

……

6d) Would you like any additional support from EQUIP after workshops, to help you put learning into practice?

❑ Yes ❑ No

6e) If you would like additional support outside the workshops, what would be the most practical and effective way for EQUIP to provide this? (Please tick one box)

- ❑ Telephone and/or E-mail conversations.
- ❑ EQUIP to come to a project meeting.
- ❑ EQUIP to make a special visit to the project (not in your meeting time).

Comments:

……

……

Section 7 — General

Is there any other training or support you would like from EQUIP in the next eight months?

……

……

……

Section 8 — About You

Name: ……

Role in project: ……

Project title: ……

Project end-date: ……

Communicating with you

EQUIP would like to telephone / E-mail you from time to time, to talk with you about the training programme.

If you DO NOT want a member of the EQUIP team to telephone or E-mail you, please tick this box. ❑

We would like all who are involved with the projects to feel free to contact us at any time about the workshop programme.

 E-mail: linsey.hovard@phru.nhs.uk

or

☎ Tel: 01865 226707.

Please return this questionnaire in the stamped addressed envelope by **6h January 2004**

Appendix 2: Summary of Responses to Learning Needs Review - December 2003

54 questionnaires sent out.
13 responses received, plus one telephone interview, as requested = 14 responses.
26% response rate.

All projects that are still running were represented, except for Project 92 (Can screening people registering with primary care improve the detection of tuberculosis? A cluster randomised controlled trial in East London PCT).

One completed project (81 'Promoting Partnership: Facilitating effective primary care provision for people with communication difficulties) is represented.

Project No.	Project completion date	Number of responses
57	Nov 04	3
58	Mar-Apr 05	3
73	Jan 04	3
81	Feb 03	2
106	Apr 04 or 05 (unclear)	2
112	Mar 04	1

Section 1 – Workshop Topics

Respondents expressed interest in the following topics:

- Writing research reports that will be read by people who do not have a research background (9).
- Writing research reports: Skills for research teams writing together, or for consumers who are writing reports (9).
- Letting people know about our work (dissemination) (8).
- Writing new research proposals with consumer-involvement in mind (8).
- Making things happen (7).
- Models of consumer involvement in research (7).
- Half-day discussion group on whatever's important to people who sign up for the workshop (1).

Priorities:

- Writing research reports (5).
- Dissemination (5).
- Making things happen (4).
- Writing new proposals (1).
- Models of consumer involvement (1).
- Addressing minority groups (1).

Section 2 – Structure of workshops

- Half-day workshop on one topic (8).
- 1-day, covering two or more related topics (2).
- 'Drop-in' day, with a few sessions happening at the same time. You choose which ones you come to (3).
- Don't mind (1).

Section 3 – Timing of workshops

Tuesday seems to be possible for most people (no-one said they could not attend on a Tuesday, though project 58 later said users and carers can only attend on Monday & Wednesday).

Three preferred mornings, one preferred afternoons.
Three preferred morning sessions to start mid-morning (e.g. 11:00 am - 2:00 pm).

Section 4 – Your involvement

Two offers:

- "addressing the needs of minority groups".
- implementation.

Section 5 – Support for putting learning into practice

- Flip-chart.
- Help with ideas on how to make the session accessible, collaborative, and to allow ideas to generate from the ground.

Section 6 – Using the workshops

6a) *Please describe how you have tried to use the things you've learned about in the workshops?*

- I haven't attended any workshops.
- I've not attended an EQUIP workshop yet – I am new in post.
- I've currently learned more about technical side of problems faced by Drs in primary care when dealing with older people.
- Presenting talks – adding "props".
- Although I'm just a consumer I like to know what research and work is taking place to feel I have been involved.

- I have only been to one. Another team member attended another and felt it didn't offer anything new to what we were already doing.
- Mainly reference practice: more conceptualisation than practical gain.
- Helped to give a new approach.
- Being more open & receptive to, and making fewer assumptions about, users' views – at our (consumer panel) meetings and in all communications with panel members.

6b) *Please describe any successes*

- Feeling more confident about focusing on right options to ask elderly people and discussing with medical professionals.
- We have achieved a measure of commitment from consumers.
- I would hope that our 'learning together' approach has informed the consumer panel's commitment to the project and the cohesion of the group.

6c) *Please describe any challenges*

- Time an ongoing challenge – not enough of it!
- Commitment needs ongoing nurturing, which is time consuming!
- The time needed to enable researcher/s to keep in contact with panel members – especially in between scheduled panel meetings – to keep up to date with project progress and relevant activity in local stakeholder organisations.

6d) *Would you like any additional support from EQUIP after workshops, to help you put learning into practice?*

Yes: 1 No: 4

6e) *If you would like additional support outside the workshops, what would be the most practical and effective way for EQUIP to provide this?* (Please tick one box)

- Telephone and/or E-mail conversations (6).
- EQUIP to come to a project meeting (3).
- EQUIP to make a special visit to the project (not in your meeting time) (2).

Comments:

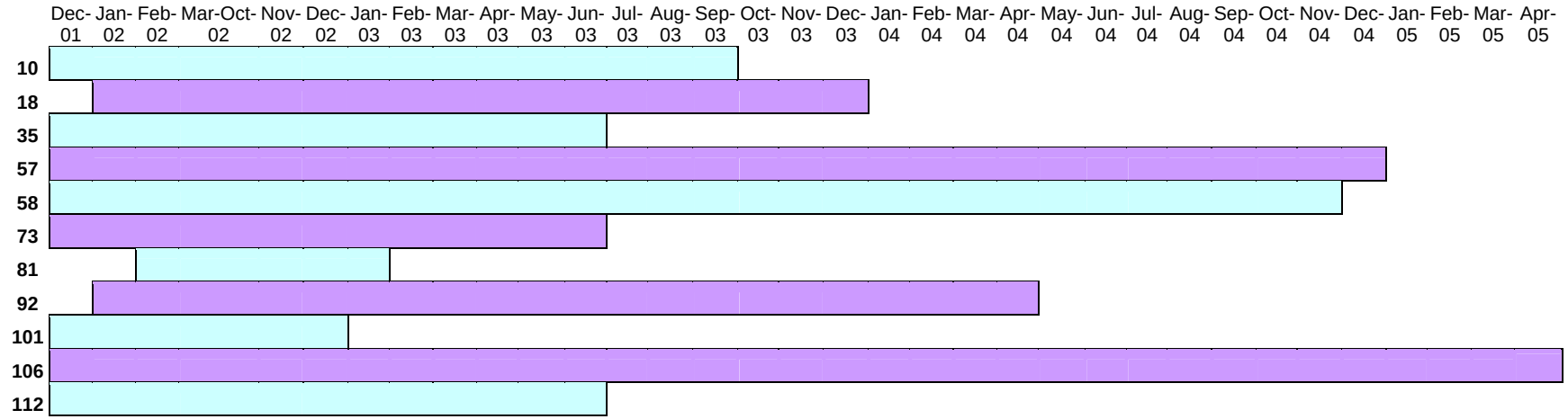
- It would be good idea for EQUIP to visit meeting and understand what problems faced by users.
- Possible re-inforcement would be helpful to ensure that I understand or use workshop material – possibly telephone calls can deal with this.
- Would be nice to be kept updated as to the results and research from the project I was involved in and what is being done with these.
- Personal support via telephone/E-mail.
- Support for consumer panel via outreach visit/s

Additional support requested from projects 57 (attend a meeting), 58 (dissemination) and 73 (endings and closures).

Section 7 – Other requests

- Training for user representatives around public dissemination of research might be helpful.
- Whatever is offered or available needs to be where most people can benefit, which is in the work place. I appreciate the value of meeting other projects, but on a practical day-to-day basis, this is less valuable to a project that is already delayed and where time is a premium. Feedback from team members is that they are already receiving the training and support they feel is necessary.
- Need to recruit a new worker – they may need some support.
- Something on 'ending' for consumer/time limited contract workers. Possibly exit interviews of some sort (e.g. by telephone).
- Dissemination to groups.

Appendix 3: Project Timescales



10 Can the outcome of postnatal depression be improved by supporting national service framework guidelines with a consultation-liaison service with health visitors?

18 Can a lay-led self-management programme for chronic illness improve the health of Bengalis? A randomised controlled trial with cost-effectiveness analysis.

35 Promoting testicular self-examination and awareness amongst young men with learning disabilities.

57 Identifying unmet health needs in older people: the development of a valid and reliable instrument for primary care.

58 Reducing the inequalities in access to primary health care services by adults with learning disabilities by the implementation of personal health profiles.

73 Exploring the risk of falls from the perspective of older people, carers and health and social care professionals.

81 Promoting partnership - Facilitating effective primary care provision for people with communication difficulties

92 Can screening people registering with primary care improve the detection of tuberculosis? A cluster randomised controlled trial in an East London PCT

101 A parent-led exploration of parents' views of the child health surveillance/ health promotions programmes offered to them during their child's first year of life

106 Developing young people's involvement in mental health in primary care: towards consumer produced quality standards.

112 To use the aesthetic component of the Index of Orthodontic Treatment Need to measure agreement between normative and perceived orthodontic need amongst 12-14 year old children from different ethnic groups in schools in Harrow & Hillingdon.

Appendix 4: Attendance at Workshops

Project No	Title	07/12/2001 workshop	13/02/2002 workshop	29/04/2002 workshop	13/08/2002 meeting	18/9/01 meeting	17/1/03 communication	5/6/2003 workshops	Analysis 10/12/03	Presentation skills	Dissemination skills	Making Things Happen
10	R	x										
10	U	x	x	x	x	x	x					
10	U				x	x						
18	L					x						
18	R	x										
19	U				x	x						
35	R	x				x						
35	U						x					
35	U	x		x			x					
35	U	x										
35	U	x					x	x		x		
35				x		x						
35	U					x	x	x				
35			x	x			x					
57	U			x				x	x		x	
57	R	x		x	x	x	x	x			x	
57	R	x										
57	U							x				
57	U	x										
57	U	x										
57	U	x	x	x	x		x	x	x	x	x	
57	U	x										
57	R							x				
57	L					x						
58	R	x										

Project No	Title	07/12/2001 workshop	13/02/2002 workshop	29/04/2002 workshop	13/08/2002 meeting	18/9/01 meeting	17/1/03 communication	5/6/2003 workshops	Analysis 10/12/03	Presentation skills	Dissemination skills	Making Things Happen
58	U	x		x								
58	U		x	x								
58	R		x			x		x				
35	C											
35	R						x					
58	Helper						x					
58	C								x	dna		
58												dna
58									dna			
58	C						x	x				
73	R	x						x				x
73	R	x						x				
73	R			x	x	x	x	x		x		x
81	R	x				x						
81	C					x	x	x				dna
81						x						
81	R		x									
92	R	x				x						
101	L					x						
101	C	x										
101	R					x						
106	R	x				x						
106	C		x	x								
106	R			x	x	x		x				
106	R								x			
106	U								x			
106	C	x										

Project No	Title	07/12/2001 workshop	13/02/2002 workshop	29/04/2002 workshop	13/08/2002 meeting	18/9/01 meeting	17/1/03 communication	5/6/2003 workshops	Analysis 10/12/03	Presentation skills	Dissemination skills	Making Things Happen
112	R	x			x	x					x	
112	R					x						
112	R					x						dna
Others (e.g. partners, helpers)						x						
									dna			
						x			dna			
							x					
						x						
							x					
						x						
						x						
						x						

Key abbreviations:

Title
R = researcher
U = user
L = lead investigator
C = carer

Analysis
dna = did not attend

- 107 -

Top Tips for Consumers

(Responses to the pre-workshop questionnaire)

COMMUNICATION

Improving communication between researchers and 'users' and understanding of process etc

Listen and learn

Collect information from your group – learn about them

Inform researchers if you lose interest and want to opt out (it could promote change)

Don't dominate discussions – give others a chance. Speak only when you have a relevant contribution

Apply your learning in your day to day life and share with your friends

Be prepared to fight your corner

COMMITMENT

Do your best to attend regularly

Appreciate that pledges to help should be fulfilled

ROLES & GOALS

Make sure people who care about the issues are selected, and prepared to commit time

Could be useful to have a kind of contract – gives a feeling of worth and sets out what's required on both sides

Acknowledge importance of our contribution as member of the research team and of user perspective and assist role.

Clarify needs with team

INFORMATION

Consumers should be given appropriate and relevant reading material

A good read: "Getting involved in research: a Guide for Consumers – produced by Consumers in NHS Research Support Unit"

How do you think the involvement of consumers has made a difference to the research project?

"Consumers were essential – after all, what is a cake without the ingredients?"

Relevance

- The project has gained from deeper, more personal insights. It is embedded in the real, lived experiences of ageing, health and falls.
- Involvement of consumers has made the process of conducting the project more meaningful to consumers, particularly to groups who can sometimes be more difficult to reach.

Real consumer focus

- The relationship between the consumer panel and the research team has been developmental and increased what we could achieve alone.
- We have developed a cohort of advocates for the agencies' efforts and for the recommendations which are flowing from the research. This increases the likelihood of successful implementation.
- Highlights the relevance of 'the personal' in professional research – counteracts objectification of users.

Educational

- Consumer involvement proved to enhance children's knowledge about the subject which is an added educational value to the public which was not accounted for in the project outcome.
- Researchers have gained a greater understanding from the broad, hands-on experience of consumers.

Challenging

- The panel's questioning and sense of urgency for action has begun to shift researchers' and service providers' ideas of accountability.

Questionnaire feedback (Question 2)

Questions and Issues.

These are some of the things you said you would do differently if you were starting the project again /

Did your project face similar issues? How did you deal with them?

Questionnaire feedback (Question 4)

Appendix 6: Evaluation Form

EQUIP Workshop: ???????????
Venue & Date

Facilitators: ????????

We would be grateful if you would take a few minutes to complete this form - it will help us to plan future workshops.

---

1. Please indicate by ticking the appropriate box, your level of satisfaction with the following aspects of the workshop:

	Extremely satisfied				Extremely dissatisfied
	1	2	3	4	5
The content of the workshop	❑	❑	❑	❑	❑
The relevance of the workshop for your role in the project	❑	❑	❑	❑	❑
The presentation of the workshop	❑	❑	❑	❑	❑
The venue: comfort and catering	❑	❑	❑	❑	❑
The venue: ease of access	❑	❑	❑	❑	❑
Your overall satisfaction with the workshop	❑	❑	❑	❑	❑

2. What did you like best about today?

PTO

3. How could we have improved the workshop?

4. What role do you see for people who do not have a research background, in research data analysis?
THIS QUESTION CHANGES DEPENDING ON WORKSHOP SUBJECT

5. Any other comments?

Thank you for your help!
Linsey Hovard and Sandy Oliver

Public Health Resource Unit
4150 Chancellor Court
Oxford Business Park South
Oxford
OX4 2JY

Tel: 01865 334739
Fax: 01865 334756

www.phru.nhs.uk