

Appendix 2: INVOLVE Job Sheets 2005 / 2006**Main Group****1. TITLE****A. Support Group members / Group meetings****2. SUMMARY (30 words)**

Ongoing work to support group members and INVOLVE meetings

3. DESCRIPTION (300 words)

Ongoing work in arranging and providing secretariat support for both main Group and sub-group meetings. This includes arranging payments of members travel expenses and attendance allowances, as well as any training required.

There are four group meetings a year, including the annual awayday as well as regular chairs meetings.

4. TIMESCALE

Date started (if applicable)	Ongoing
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5. MILESTONES (if known)

Month	Activity
March 8th	Group meeting
June 7th	Group meeting
October 5th / 6th	Away day
November 29th	Group meeting

6. ORIGINS

Which sub-group	Main group
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7. CO-ORDINATORS

Support Unit	Sarah Buckland
Group member	Nick Partridge

8. BUDGET

£30,000

Main Group

1. TITLE

B. UK Clinical Research Collaboration (UKCRC)

2. SUMMARY (30 words)

To promote and support active public involvement within the UKCRC across the different workstreams, and to provide support to clinical research and development arising from the increased R&D funding in the UK.

3. DESCRIPTION (300 words)

UKCRC Board and Core Team

INVOLVE will seek to work with the core team to encourage and support public involvement across the UKCRC workstreams, taking forward initiatives as appropriate.

- Nick Partridge is a member of the UKCRC Board
- Sarah Buckland is a member of the Regulatory and Governance working group of the UKCRC.

UKCRN

INVOLVE will work with the UKCRN Coordinating Centre to develop plans for supporting both the work of the consumer lead within the UKCRN CC and within the networks themselves. This could involve responding to the support needs of the networks through for example developing guidance, and providing workshops, providing specific support to the individual networks, and the sharing of good practice.

- Sarah Buckland is to be an advisor on the Medicines for Children research network

Supporting clinical R&D in the UK

The increase in R&D funding for clinical research and its infrastructure will mean that the scale of research in the UK will increase substantially over the next few years. INVOLVE will seek to respond to the associated increase in demand for support and advice on public involvement in clinical research, through sharing and promoting existing resources as well as exploring the need for additional support.

4. TIME SCALE

Date started (if applicable)	April 2004
Length of project (months)	Ongoing

5. MILESTONES (IF KNOWN)

Month	Activity

6. ORIGINS

Which sub-group	Main Group
When 1st agreed	

7. CO-ORDINATORS (IF KNOWN)

Support Unit	Sarah Buckland
Group member	Nick Partridge

8. BUDGET

Amount	None
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Empowerment

1. TITLE

C. Improve accessibility of INVOLVE materials, processes and events

2. SUMMARY (30 words)

This project addresses INVOLVE's commitment to making the information that it produces, its processes and events, genuinely accessible to different audiences according to their communication requirements.

3. DESCRIPTION (300 words)

INVOLVE is committed to ensuring that the information it produces is accessible to a range of audiences with specific communication requirements, and similarly that its organisational processes and events are genuinely accessible. It is necessary to acknowledge that there are limitations on what INVOLVE can achieve in terms of human, material and financial resources. However, this project takes on responsibility for improving INVOLVE's knowledge, understanding and delivery on accessibility issues within those resource limitations.

In 2005/06 the focus of this work will be:

1. To establish an Accessibility Working Group

- This Group will be comprised of members of INVOLVE and the Support Unit who have particular knowledge, skills and interest in the issue of accessibility.
- The group will meet up to four times a year.
- The purpose of the group will be to:
 - Develop INVOLVE's accessibility strategy and programme
 - Continue to develop disability equality training and accessibility training for INVOLVE members
 - Address the issues of accessibility in relation to INVOLVE's processes, events and publications
 - Establish priorities for INVOLVE's accessibility programme
 - Monitor and review INVOLVE's progress on an annual basis

2. To establish a network of accessibility consultants

- The Accessibility Working Group will develop an accessibility network.
- This will be a network of people, including disabled people, who are not members of INVOLVE but who have specialised knowledge in one or more areas of impairment and an interest in access.
- The purpose of this network will be to act as advisors and a sounding board in relation to the work of INVOLVE.
- Members of the accessibility network will be consulted as appropriate.

4. TIME SCALE

Date started (if applicable)	April 2005
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5. MILESTONES (IF KNOWN)

Month	Activity
Spring 2005	Establish the Accessibility Working Group
Summer / Autumn 2005	Commission an accessibility audit of INVOLVE
Throughout year	Meetings of the accessibility working group
March 2006	Annual report on activities and delivery of a draft accessibility strategy for INVOLVE

6. ORIGINS

Which sub-group	Empowerment
When 1st agreed	On going commitment annually renewable in March.

7. CO-ORDINATORS

Support Unit	Roger Steel
Group member	Susie Parr

8. BUDGET

Amount?	£12,000
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EMPOWERMENT

1. TITLE

D. Leaflet for the public on involvement in research

2. SUMMARY (30 words)

A leaflet on getting involved in research for the public, designed so that researchers can give out the leaflet with their own contact details on it.

3. DESCRIPTION (300 words)

The leaflet would explain how service users, patients, carers, and the public can get involved in research and why this is important. The leaflet would also have space for researchers or the distributing research organisation to include their own contact details, using a stamp or sticky labels.

The leaflet would have the advantage of

- helping the public to become more aware of health and social care research
- helping to build capacity for public involvement in research, both locally and nationally
- explaining public involvement in INVOLVE's own words and according to INVOLVE's principles
- acting as a helpful introduction to involvement and pointing to further information
- being a useful resource at events.

The leaflet could be dispatched to research organisations and individual researchers for their own use locally and nationally when engaging the public.

4. TIMESCALE

Date started (if applicable)	April 2005
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5. MILESTONES (if known)

Month	Activity
April / May 2005	Write draft
June 2005	Consultation & feedback on draft
August 2005	Final draft
September 2005	Printing

6. ORIGINS

Which sub-group	Empowerment
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7. CO-ORDINATORS

Support Unit	Roger Steel
Group member	Susie Parr

8. BUDGET

£2,200

EMPOWERMENT**1. TITLE****E. National training follow up event****2. SUMMARY (30 words)**

A small networking event to follow on from the training seminar in 2004. The purpose would be to encourage trainers and training commissioners to think further about developing their work in training for public involvement in research.

3. DESCRIPTION (300 words)

Following the interest and enthusiasm which was generated at the INVOLVE training seminar on 22nd April 2004, it is thought that a smaller and less complex event could be arranged in 2005 in order to encourage networking and practice sharing among trainers.

This might be in the form of a networking lunch, perhaps with an opportunity for trainers to bring along leaflets and posters.

It will also be a useful event for publicising the INVOLVE training database.

In terms of continuing to build training capacity this event could be a further milestone.

4. TIMESCALE

Date started (if applicable)	May 2005
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5. MILESTONES (if known)

Month	Activity
April 2005	Venue arranged
	Mail out to list
November/December 2005	Event

6. ORIGINS

Which sub-group	Empowerment
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7. CO-ORDINATORS

Support Unit	Roger
Group member	Mary Nettle

8. BUDGET

£5,000

Empowerment

1. TITLE

F. Public Information pack: Phase 1 (Dissemination and printing)

2. SUMMARY (30 words)

A replacement for 'Getting Actively Involved in Research: A Guide for Consumers'. This project would finance the design and printing of an information pack to be produced by the Support Unit.

3. DESCRIPTION (300 words)

The INVOLVE publication 'Getting Actively Involved in Research: A Guide for Consumers' will be out of print in a matter of months. Much of the information in it is out of date. It is proposed that INVOLVE break from producing a single, mass printed booklet style guide to a more flexible, accessible, up to date and interesting approach to guidance based on an information 'pack'.

Producing such a pack could be achieved in stages by producing a number of small booklets which serve to give different types of information. Eg. Basic Principles, Practicalities, Examples, The Research Cycle, Useful Contacts. These could then be put together in a well designed folder along with other information sheets sometimes tailored to suit a particular request. In this format, it would be easier and cheaper to update the pack since it will be made up of 'modules', and it would be easier to make packs up to meet individual access needs, such as large print, and picture text.

This job sheet refers primarily to the costs of covering design, and possibly some printing costs. Producing such a pack is an intensive use of Support Unit time, but this is not included in the job sheet.

4. TIME SCALE

Date started (if applicable)	May 2005
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5. MILESTONES (IF KNOWN)

Month	Activity
Spring 2005	Set up an advisory panel
Summer 2005	Identify core booklets required
Autumn 2005	Work begins on writing and / or redrafting core booklets
Winter 2005 / Spring 2006	Begin work on design for the booklets
Spring 2006	Begin printing

6. ORIGINS

Which sub-group	Empowerment
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7. CO-ORDINATORS

Support Unit	Philippa Yeeles
Group member	

8. BUDGET

Amount?	£5,000
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Empowerment

1. TITLE

G. Public information pack: Phase 2: (exploring different media)

2. SUMMARY (30 words)

INVOLVE's first multi media information CD rom to complement the new public information pack for the public, being produced by the Support Unit. It would provide multi layered levels of information about public involvement in research.

3. DESCRIPTION (300 words)

It is likely this project will only just be started in this financial year. It will be necessary to establish costs, approach, content, and the supplier during this year.

The cd rom would provide accessible multi media learning and contain different layers of information so that users can choose the level of complexity they want. It would contain sound and commentary, video clips, animated diagrams, subtitles, written material, and links to the INVOLVE website. Navigation would be clear simple and easy to use.

The cd rom could be distributed at events, with the information pack, with other publications and singly by post.

4. TIME SCALE

**Date started
(if applicable)**

April 2005

5. MILESTONES (IF KNOWN)

Month	Activity
July – August 2005	Develop 'map' to identify components needed.

6. ORIGINS

Which sub-group	Empowerment
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7. CO-ORDINATORS

Support Unit	Roger Steel
Group member	

8. BUDGET

Amount?	£5,000
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Empowerment

1. TITLE

H. Think piece on INVOLVE developing position statements

2. SUMMARY (30 words)

To develop a think piece on the feasibility and appropriateness of developing INVOLVE position statements on issues such as minimum terms and conditions for involvement and payments.

3. DESCRIPTION (300 words)

The think piece was requested at the chair's meeting in January 2005 when a proposal from empowerment to produce two pieces of work – one on minimum terms and conditions and the other on minimum payments for people getting actively involved in research were not prioritised for the financial year 05/06. Concerns were expressed that position statements were a change of approach for INVOLVE which has always been an advisory body. There was a need to explore what it might mean to lay down specific standards as there were likely to be implications for the organisation internally, and in how the organisation operated externally.

4. TIMESCALE

Date started (if applicable)	May 2005
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5. MILESTONES (if known)

Month	Activity
May	Draft written
	Consult
	Final Draft

6. ORIGINS

Which sub-group	Empowerment
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7. CO-ORDINATORS

Support Unit	Roger Steel
Group member	Kirstine Knox and Karen Collins

8. BUDGET

NIL

Strategic Alliances

1. TITLE

I. Guidance for public involvement in commissioning research

2. SUMMARY (30 words)

Building on work started in 2004, to develop guidance notes for members of the public, commissioners and researchers on peer review, commissioning boards and grant applications.

3. DESCRIPTION (300 words)

This work is continuing to identify further issues and examples (from those highlighted in INVOLVE's report of the Commissioning Workshop, July 2003) of what has worked well and to obtain supporting documentation and to produce guidance documents on: public involvement for grant applicants and commissioning boards, and public involvement in peer reviewing. The draft guidance will be finalised by the end of May 2005. In length the guidance notes will cover about 6-8 sides of A4. The following sets of draft guidance notes will be produced:

- Public involvement in peer reviewing
(1 version for the public and 1 version for commissioners)
- Public involvement in commissioning boards
(1 version for the public and 1 version for commissioners)
- Public involvement in grant applications
(1 version for the public (as applicants), 1 version for commissioners and 1 version for researchers)

4. TIME SCALE

Date started (if applicable)	December 2003
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5. MILESTONES (IF KNOWN)

Month	Activity
April - June 2005	Circulating draft guidance for comment
July/August 2005	Final revisions to guidelines
September 2005	Production/publication of guidelines
October 2005	Dissemination

6. ORIGINS

Which sub-group	Strategic Alliances
When 1st agreed	March 2003

7. CO-ORDINATORS

Support Unit	Jane Royle & Maryrose Tarpey
Group member	Vinod Kumar

8. BUDGET

Amount	£8,000
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Strategic Alliances

1. TITLE

J. Guidance for ethics review bodies – involving service users

2. SUMMARY (30 words)

It is intended that the guide will address two things:

- Firstly, to identify the principles and practicalities of the effective involvement of service users in ethical review bodies.
- Secondly, to highlight service user considerations when reviewing research applications.

3. DESCRIPTION (300 words)

In 2002 and 2003 INVOLVE facilitated two consultation workshops with social care service users and carers on behalf of the Department of Health in order to elicit views on ethics and ethical frameworks for social care research. Views and conclusions from these workshops were fed into discussions for the development of an Implementation Plan for the Research Governance Framework specifically for social care research.

An aspect of the discussion at the workshops focussed on the need for direct service user representation on ethical review bodies. It was the view of many workshop participants that inclusion of service users would help ensure that the service user perspective was included in any deliberations on the ethical aspects of research proposals. It was also the view of participants that involvement of service users should be done well, equitably, and in a way that was effective and valuable for all stakeholders. It was identified that a guide to involving service users on research ethics review bodies was needed. It would not only address aspects of involvement on the bodies themselves, but would also provide some guidance on reviewing research proposals that have implications for service users.

A further development which relates to this project is the piece of work that INVOLVE has commissioned on the definitions of user controlled research. This piece of work is likely to be relevant to perceptions of user research when ethical review bodies receive research applications identified as 'user led', or 'user controlled'.

- **Aims of guide:**

1. to provide a helpful, practical guidance 'tool' for professionals engaged in promoting and working towards user involvement in ethical review.
2. to provide written practical guidance about how to involve service users in ethical review bodies

3. to provide written practical guidance on assessing applications where there is service user involvement

4. TIME SCALE

Date started (if applicable)	March 2005
Length of project (months)	1 year

5. MILESTONES (IF KNOWN)

Month	Activity
April 05	Agree commissioning brief
May/June 05	Send out invitations to tender
July 05	Work starts with literature review
September 05	Summary and 1st draft
October 05	Wider consultations and 2 nd draft
December 05	Consultation workshop?
January 06	final draft

6. ORIGINS

Which sub-group	Strategic Alliances
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7. CO-ORDINATORS

Support Unit	Roger Steel
Group member	Carol Lupton

8. BUDGET

Amount?	£12,000
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Strategic Alliances

1. TITLE

K. INVOLVE conference

2. SUMMARY (30 words)

INVOLVE has a national conference every two years. It provides a forum for people who are interested in public involvement in research to debate current practice, future challenges and opportunities.

3. DESCRIPTION (300 words)

The conference is a non profit making event which is partly funded by conference fees and partly subsidised by the Department of Health. The conference is managed through a sub committee of INVOLVE – the Conference Planning Group.

In January 2005 the Conference Planning Group confirmed that INVOLVE's fifth conference will take place in autumn/winter 2006.

In 2005/06 the following work will be undertaken:

- Agreeing on dates for the conference
- Finding and booking a suitable venue
- Agreeing the theme and format of the conference
- Drafting the programme
- Putting out a call for proposals
- Drafting the registration form

4. TIME SCALE

Date started (if applicable)	ongoing
Length of project (months)	24 month cycle

5. MILESTONES (IF KNOWN)

Month	Activity
Spring/Summer '05	Identify conference venue and date
Autumn '05	Conference Planning Group's 1 st meeting
Winter '05	Draft conference programme Draft call for proposals
Spring '05	Disseminate call for proposals Draft booking form

6. ORIGINS

Which sub-group	Strategic Alliances
When 1st agreed	Rolling commitment since 1 st conference. Budget agreed annually.

7. CO-ORDINATORS

Support Unit	Philippa Yeeles
Group member	Lester Firkins
Conference Planning Group	Kate Sainsbury (Chair)

8. BUDGET

Amount?	£10,000 (for deposit on a conference venue)
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Strategic Alliances

1. TITLE

L. Discussion Forum

2. SUMMARY (30 words)

INVOLVE is interested in hosting a computer based discussion forum through which individuals and organisations can develop or maintain an interest in public involvement in research.

3. DESCRIPTION (300 words)

INVOLVE currently mails out its quarterly newsletter to approximately 3,000 people. These people would be the initial target participants for any discussion forum.

Members of INVOLVE have expressed interest in developing either a web or email based discussion forum. The Strategic Alliances sub group see this as an opportunity to engage with a wider audience and also to develop a unique resource for people interested in public involvement in research. Alongside this, the Monitoring & Evaluation sub group are developing a special interest forum for people with a particular interest in monitoring and evaluation of public involvement in research.

This project will have two distinct phases:

Phase 1 –

The Support Unit will carry out preparatory work exploring the options available. The following issues, *inter alia*, will be addressed:

- ▶ What is the purpose of INVOLVE hosting forums?
- ▶ Who do we expect to participate and for what purpose?
- ▶ What will distinguish this discussion forum from others?
- ▶ How would we host the forum? A forum host, or moderator, is someone who takes primary responsibility for the care and feeding of a discussion group. The host sets the tone, establishes ground rules, initiates topics of discussion, encourages participation, and tries to ensure that the forum serves the purpose for which it is intended. This role is especially important in the early stages, as it takes a

considerable amount of planning and effort to get a forum off the ground.

- ▶ What technology is needed or most appropriate? Anyone can set up an email list using freely available basic systems – e.g. Yahoo/Google. The alternative is to use more advanced software - e.g. Web Crossing – and or the services of a company that will host discussion forums for you – e.g. Community People.
- ▶ Researching the advantages and disadvantages of existing fora. E.g. R&D Forum, Mental Health Foundation

Phase 2

- The Support Unit will recommend a preferred course of action to the Strategic Alliances sub group from which process setting up of the discussion forum proceeds.

4. TIME SCALE

Date started (if applicable)	
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5. MILESTONES (IF KNOWN)

Month	Activity
April/May/June	Support Unit carry out research
July/August/September	Support Unit develop recommendations
October 2005	Strategic Alliances comment on recommendations
December 2005	Contract for work to be undertaken to set up the discussion forum
January/February 2006	Discussion forum goes live

6. ORIGINS

Which sub-group	Strategic Alliance
When 1st agreed	

7. CO-ORDINATORS

Support Unit	Philippa Yeeles
Group Member	Juliet Whitworth

8. BUDGET

Amount?	£2,500 (cost of setting up basic technology linked to web site)
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Strategic Alliances

1. TITLE

M. Public health research consortium

2. SUMMARY (30 words)

A project to develop INVOLVE's public health strategy and action plan in 2005/06 by pump priming public involvement in research in the work of the Public Health Research Consortium.

3. DESCRIPTION (300 words)

INVOLVE has a 'Public Health Strategy and Action Plan' and this project will contribute towards its further development in 2005/06.

The Department of Health Policy Research Project is in the process of commissioning a Public Health Research Consortium. INVOLVE has had a role in the commissioning process as a participant on the commissioning board. The Consortium will focus on strengthening the evidence base for health improvement and the narrowing of health inequalities. Initially it will undertake research on tackling health inequalities, risk and health, and incentives and regulation.

INVOLVE has offered to work with the consortium during 2005/06 in order to pump prime the development of public involvement within its research programme. INVOLVE will negotiate with the consortium and the Policy Research Programme on the nature and extent of this collaboration.

The preferred bidders for the Public Health Research Consortium have indicated that they wish to set up a children and young people's reference group to work with them. INVOLVE will support the consortium with this project.

Ruth Sinclair and Catherine Law are taking a lead on public involvement in the work of the consortium.

4. TIME SCALE

Date started (if applicable)	
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5. MILESTONES (IF KNOWN)

Month	Activity
Summer 2005	Discussion with consortium on development of the children and young people's reference group
Autumn 2005	Consortium becomes active

6. ORIGINS

Which sub-group	Strategic Alliances
When 1st agreed	

7. CO-ORDINATORS

Support Unit	Philippa Yeeles
Group member	Ruth Sinclair

8. BUDGET

Amount?	£10,000
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Strategic Alliances

1. TITLE

N. The James Lind Alliance

2. SUMMARY (30 words)

The James Lind Alliance is a coalition of organisations representing patients and clinicians collaborating to confront important uncertainties about the effects of treatments. INVOLVE is a founder, co-convenor of the Alliance.

3. DESCRIPTION (300 words)

The James Lind Alliance was formed in April 2004. It is an initiative to open up discussion between patients and clinicians to agree on priorities for future research on the effects of treatments.

Initially the Alliance is being co-convened by INVOLVE, the Royal Society of Medicine and The James Lind Library. If by the end of 2006 the Alliance has begun to fulfil its objectives, Alliance members (pairs of organisations representing patients and clinicians) will then assume responsibility for the Alliance's management and development, taking over that role from the current co-convenor organisations.

The Alliance will be formed from a gradually increasing number of partnerships between organisations representing patients and organisations representing clinicians, working together to confront important uncertainties about the effects of treatments.

The Alliance will pursue its objectives through a process of meetings. These meetings will be held at the Royal Society of Medicine and will be jointly convened by an organisation representing patients and an organisation representing clinicians, who both share a common interest in a particular health problem or problems. The two partner bodies will decide the details of the agenda, and who should attend. Each meeting will be facilitated by a chair who has no vested interest in the particular decisions reached by participants. Each meeting will conclude with an agreement to take forward a joint action plan.

INVOLVE will work with the Royal Society of Medicine and the James Lind Library to promote and support the Alliance. Nick Partridge and Lester Firkins

sit on the Alliance's shadow steering group. Sarah Buckland and Lester Firkins will attend and assist with initial partnership planning meetings.

From early JLA meetings, the following specific activities have been discussed as possible ways in which INVOLVE can support the Alliance.

- Help to identify and remain alert for prospective partners who would benefit from participating in a JLA working partnership.
- Share with the JLA any experience INVOLVE has in the work of prioritisation.
- Assist voluntary organisations to achieve effective public (e.g. patients, carers and service users) involvement in the development of JLA partnerships
- Provide support and guidance on running accessible meetings with patients, and clinicians.

4. TIME SCALE

Date started (if applicable)	April 2004
Length of project (months)	Initially to December 2006

5. MILESTONES (IF KNOWN)

Month	Activity
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6. ORIGINS

Which sub-group	N/A Came to Strategic Alliances sub group from the main group
When 1st agreed	December 2004

7. CO-ORDINATORS (IF KNOWN)

Support Unit	Sarah Buckland Philippa Yeeles
Group member	Lester Firkins

8. BUDGET

Amount	None
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Monitoring and Evaluation

1. TITLE

O. Seminar on the impact of public involvement

2. SUMMARY

This seminar will present the findings of public involvement in research from two large programme evaluations. It will also discuss the developments within the main approaches to public involvement in research – consultation, collaboration and user-controlled.

3. DESCRIPTION

The seminar will take place on the 23rd of June 2005. John Sitzia to welcome and provide a brief introduction to the day.

The aim of the morning sessions is to disseminate the findings of two major evaluations on public involvement in research. The evaluation of consumer involvement in 11 London Primary Care Research projects (PC11) and the evaluation of 12 research projects funded by the Department of Health Valuing People Programme and carried out by the Learning Disability Research Team, with Values Into Action (VIA). Both these studies are due to finish in March 2005. (INVOLVE has project managed the first evaluation and provided a support link to the second evaluation through VIA). John Sitzia will chair the PC11 presentation. Carol Lupton will chair the LDRT presentation.

The afternoon will focus on the different approaches to public involvement in research. The afternoon will be introduced and facilitated by Derek Stewart. Carey Ostrer will lead the discussion on collaborative approaches to public involvement in research followed by Michael Turner and Peter Beresford on user-controlled research. A final discussion will be lead by Derek Stewart.

Approximately 70 people have booked a place. This includes researchers, service users and a small number of commissioners. Presenters have been asked to present their findings in an accessible way to take account of the audience which includes a number of people with learning difficulties.

4. TIME SCALE

Date started (if applicable)	December 2004
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5. MILESTONES (IF KNOWN)

Month	Activity
December 2004	Venue booked for June 23 rd 2005, London Resource Centre London N7
January 2005	Work up specification for materials & papers
February – May 2005	Advertise event; meet / brief presenters, final mailout to participants 31 st May 2005
June 2005	Hold seminar (23 rd June) and produce a summary of the event. Evaluation of approach to event including assessment on accessibility (for information - INVOLVE main group)

6. ORIGINS

Which sub-group	M&E
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7. CO-ORDINATORS

Support Unit	Maryrose Tarpey
Group member	John Sitzia

8. BUDGET

Amount?	£10,000 (ring fenced funding from Primary Care evaluation and Values Into Action evaluation)
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Monitoring and Evaluation

1. TITLE

P. Forum / network for researchers

2. SUMMARY (30 words)

The development of a forum / network for researchers with an interest in researching public involvement in research. To facilitate the sharing of knowledge and expertise, to increase awareness of work being undertaken and to facilitate discussion around effective methods for evaluating public involvement in research.

3. DESCRIPTION (300 words)

The Monitoring & Evaluation Sub-Group (M&E) of INVOLVE has been considering for some time, the idea of facilitating a 'Network' of people who have an interest in public involvement in research as a research topic. Such an initiative is in keeping with the aim of M&E, to support and encourage the development of an evidence base for public involvement in research.

At the same time as M&E have been discussing this idea, as a quite separate and unrelated activity Worthing & Southlands Hospitals NHS Trust (WASH) has been trying to develop a multi-party research 'programme' in patient and public involvement in research. There is clearly substantial overlap between the INVOLVE and WASH initiatives. Consequently, INVOLVE and WASH have agreed to work together to develop and support a network. The network would be open to researchers, user-researchers and others with an interest in researching public involvement in NHS, public health and social care research.

It is anticipated that the network would involved a wider audience through:

- An email discussion list
- A dedicated website page
- An electronic library of relevant documents
- A regular workshop or event

4. TIME SCALE

Date started (if applicable)	May 2005
Length of project (months)	Ongoing

5. MILESTONES (IF KNOWN)

Month	Activity
	Liaise with interested parties
	Development of web pages
	Development of email discussion list
	Collection of relevant documents
	Promotion of above
	Launch of network
	Annual event

6. ORIGINS

Which sub-group	Monitoring and Evaluation
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7. CO-ORDINATORS

Support Unit	Sarah Buckland/Helen Hayes
Group member	Chris Caswill

8. BUDGET

Amount?	£2,000 website development £4,000 event
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Monitoring and Evaluation

1. TITLE

Q. Public motivations to get actively involved in research: A rapid review

2. SUMMARY (30 words)

Whilst it is valuable to identify where the public are involved in research and in what ways, it is equally important to gain an understanding of WHY they choose to get actively involved in research.

3. DESCRIPTION (300 words)

Anecdotally we may know of instances where people become involved following personal experience (or that of a friend or family member) of needing health or social care. It is surmised that some people may want to 'give something back'. Yet many people participate in research who do not fit these categories and furthermore often receive no direct benefit merely assurance that findings may benefit future health or social care users. Do people get involved through a reluctance to say 'no' to contributing to something for the greater good? Does the type of research e.g. clinical or social, affect motivation and the decision to participate or not? Or does it depend on the person doing the asking e.g. how likeable they are or the manner of approach? It is proposed that what motivates people (ie influences their decision to be involved) to get actively involved in research is little understood. Yet to comprehend factors influencing motivation would mean that we could enhance those drivers for active public involvement.

It is proposed that a rapid review is carried out to look at what research has been carried out and what literature is already available in this area. The review would provide an overview of available literature on this topic. It would also identify any gaps in the information available and if there are areas that require further research.

4. TIME SCALE

**Date started
(if applicable)**

July 2005

5. MILESTONES (IF KNOWN)

Month	Activity
July 2005	Draft specifications, to be worked up with involvement of link sub group member and circulated to M&E sub group members
August - September	Agree final specifications with M&E link sub-group member
Sept 2005 – January 2006	Rapid review and draft report
January – February 2006	Review and comments on draft / final version
March 2006	Dissemination and article for publication

6. ORIGINS

Which sub-group	Monitoring and Evaluation
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7. CO-ORDINATORS

Support Unit	Maryrose Tarpey
Group member	Sophie Staniszewska

8. BUDGET

Amount?	£10,000
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Monitoring and Evaluation

1. TITLE

R. Publication of articles on public involvement in research

2. SUMMARY (30 words)

A scoping study to explore and review the publication of articles in relation to public involvement in research

3. DESCRIPTION (300 words)

This scoping study would:

- consider where articles are published,
- how many are published indicating public involvement.
- does the current criteria and format for submitting articles to journals accommodate this form of reporting
- where are experiences and stories of public involvement published
- what are editors or editorial boards views on publishing public involvement in research articles

This proposal developed from the initial idea for a journal or annual publication of public involvement in research articles, which was recognised as a significant piece of work.

The review would also outline options for INVOLVE if they wanted to take this work further.

Guidance on where to seek publication and working with editors.

4. TIME SCALE

Date started (if applicable)	July 2005
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5. MILESTONES (IF KNOWN)

Month	Activity
July 2005	Draft specifications to be worked up and discussed with sub group link persons (Alison Faulkner and Tracey Williamson) before being sent out to sub-group members for comment
September 2005	Finalise specifications with M&E sub-group link persons
Oct – January 2006	Scoping study and draft report
February 2006	Review and comments on draft/ final version
March 2006	Dissemination and article for publication

6. ORIGINS

Which sub-group	Monitoring and Evaluation
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7. CO-ORDINATORS

Support Unit	Helen Hayes
Group member	Alison Faulkner Tracey Williamson

8. BUDGET

Amount?	£10,000
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Monitoring and Evaluation

1. TITLE

S. Dissemination strategy: Development of a strategy for dissemination and publication of INVOLVE reports

2. SUMMARY (max 30 words)

To develop a strategy for dissemination and publication of INVOLVE reports and to print and disseminate new publications.

3. DESCRIPTION (max 300 words)

INVOLVE will have several reports finalised during 2005 and 2006 (e.g. the User controlled research, Folk.us evaluation, Evaluation of Primary Care Research projects, review of motivations to get actively involved in research). It is recognised that different approaches and methods for dissemination of the findings will be required. The challenges for dissemination will be explored and a strategy developed that encompasses dissemination and publication needs from different perspectives. It is likely that the strategy will include the development of databases and network information as well as innovative and collaborative dissemination and publication ideas. This budget also includes the cost of printing copies of the reports.

4. TIME SCALE

Date started (if applicable)	June 2005
Length of project (months)	

5. MILESTONES (IF KNOWN)

Month	Activity
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6. ORIGINS

Which sub-group	Monitoring and Evaluation
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7. CO-ORDINATORS

Support Unit	Helen Hayes
Group member	Peter Beresford

8. BUDGET

Amount?	£6,000
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