

INVOLVE

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RAPPORT: ReseArch with Patient and Public invOlvement: a RealisT evaluation

Chief investigator

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1 Research summary

Public involvement in research (PIR) is resource and time intensive. It is important to provide evidence on how to maximise the benefits, increase access for marginalised groups and provide evidence based resources on how to integrate user involvement within different methodologies and topic areas. This project seeks to evaluate how different approaches to public involvement in research with different populations influences the identification of priorities, research conception, design, process, findings and knowledge transfer. Six exemplar research areas (diabetes, arthritis, cystic fibrosis, dementia, public health and learning disabilities) that reflect a wide range of patient/user groups, approaches to public involvement and research design will be investigated to identify what PIR approaches have applicability across all research domains, which are context specific and whether different types of public involvement achieve different outcomes for the research process, findings, dissemination and implementation of PIR.

Objectives

The study objectives are to:

- 1. Determine the variation in types and extent of public involvement in funded research in the areas of diabetes, arthritis, cystic fibrosis, dementia, public health and learning disabilities.
- 2. Describe key processes and mechanisms of public involvement in research.
- 3. Critically analyse the contextual and temporal dynamics of public involvement in research.
- 4. Explore the experience of public involvement in research for the researchers and members of public involved.
- 5. Assess the mechanisms which contribute to public involvement being routinely incorporated in the research process.
- 6. Evaluate the impact of public involvement on research processes and outcomes.
- 7. Identify barriers and enablers to effective public involvement in research.

Research Design

Utilising a critical realist framework the research is designed to focus on the mechanisms embedded within an intervention such as PIR, facilitating an understanding of outcomes that may or may not occur depending on how they are triggered, blocked or modified.

To demonstrate what elements of PIR influence research outcomes regardless of setting, those that are context specific, and what different approaches can and cannot achieve, six exemplar areas have been selected that by their focus and research tradition capture the full continuum of PIR. These are:

- **1.** Cystic fibrosis.
- 2. Diabetes.
- 3. Arthritis.
- 4. Dementia.
- **5.** Learning disabilities.
- 6. Public Health.

Stage 1

A national scoping will be undertaken of studies within the 6 exemplar areas currently funded or completed within the last 2 years. Details of each study will be electronically searched via funding body databases and relevant documentation will be reviewed for the type of research and any evidence of the nature and extent of PI. A scoping framework will be used to assess the stages of the research at which PIR took place, whether involvement was of lay groups or lay individuals and where it was located on the continuum of PI from user-led to minimal PIR. Evidence will also be collected on the range of resources supporting PIR.

Stage 2

A survey will be undertaken of investigators leading studies in the six exemplar topic areas. The survey will be undertaken in four regions of England which have been purposively selected to ensure maximum variation:

- North East.
- London.
- East of England.
- South West.

An on-line survey tool will be used to assess lead investigators' understanding of PI and the perceived impact on their study. Results from the survey will be compared to the national scoping exercise in Stage 1.

Stage 3

In-depth case studies will be conducted across the four regions. A sampling frame developed from the previous stages will be used to purposively select up to 20 case studies where the case is a single research study. This will enable maximum variation but also allows for comparison within and between region, topic area and type of research. An in-depth realist evaluation of the context, mechanisms and outcomes in particular research settings will increase understanding of at what points PIR has the most impact and effect on outcomes. Data will be collected through semi-structured interviews with up to 6 key informants per case study. Depending on the study this will include the PIR members, lead/senior researcher, steering/project management group member, clinical partners and link person in the funding organisation. Through regular contact with a nominated member of the case study, PIR processes will be tracked over an 18 month period. Analysis of key documents such as steering group minutes will also be undertaken.

Expected outcomes

One of the major outputs of this study will be a checklist or guide to what types of public involvement work best at which stages of the research process. This will help users to decide which types of research they might want to be involved with, some of the practical implications, and what the possible benefits will be for them. Supplemented with case studies, it will provide clear guidance for service users, researchers and funders on:

- different approaches to PIR,
- what needs to be in place for effective PIR,
- how PIR can be incorporated into research organisational processes,

 what kind of impact can be expected from what type of involvement and under what circumstances, and range of costs involved.

2. Background

To address the a democratic deficit within the NHS (Baggott 2004, Wilson et al. 2007), the power asymmetry between clinician and patient (Beresford 2002, Coulter 2002, Wilson 2001), and learning from mental health and disability groups, public involvement within health research has become integral to policy and research funding (Boote et al. 2002). Claims made for the benefits of PIR include: improving the relevance, appropriateness and conduct of research; refining research questions; ensuring the acceptability of the design to research participants; bringing personal benefits to members of the public involved; contributing to ethical debates and ensuring research meets policy targets (Staniszewska et al. 2007, Smith et al. 2008, Staley 2009, McKevitt et al. 2009, Entwistle et al. 1998, Trivedi and Wykes 2002). However, how PIR is implemented within health service research is variable and reflects a continuum of levels of public participation. This can range from studies where the service user is seen as: leading the research agenda (McCourt 2000, Pitt et al. 2007); as an equal collaborator and partner in developing and executing the project (McKevitt et al. 2009); as a consumer of services qualified to comment on what is proposed (Hewlett et al. 2005); or as a member of the public who provides a non-professional, non-expert perspective (Staniszewska et al. 2007, Smith et al. 2008, Staley 2009, Entwistle et al. 1998). This has been described as a 'ladder of participation' extending from public consultation to service-user-led research (Arnstein 1969), an idea elaborated further in a framework also encompassing the researcher's degree of engagement with PIR (Oliver et al. 2008). Whilst there is a robust understanding of how public involvement in research can be structured, what is not clear is the influence and impact that different approaches have and what prerequisites may ensure it is maintained and embedded as normal practice in research (Howe et al. 2006, Howe et al. 2010, May et al. 2007).

There is a lack of detailed evidence on the processes involved or of the outcomes of PIR on the research process and end-product (Nilsen et al. 2006, Staley 2009). This is in part due to the inherent difficulties in attributing outcomes to PIR (Staniszewska 2009) but other challenges that can broadly be summarised as a lack of conceptualisation of PIR (Staniszewska 2009, Smith et al. 2008), or consensus about desired outcomes, as well as researcher resistance to public involvement (Thompson et al. 2009). One recent study that aimed to develop some consensus on indicators of successful public involvement (Telford et al. 2004, Boote et al. 2006) suggested eight principles of successful involvement including:

- documented roles within the research;
- reimbursement;
- acknowledgment in reports of public contribution;
- training for the public and researchers;
- evidence of advice given by the public and taken by researchers;
- dissemination in appropriate formats.

This proposal builds on recent work on advancing the conceptualisation of PIR and measures of impact (PIRICOM study) (Brett et al. 2010, Staniszewska et al. 2008). From this systematic review we know that there are descriptive accounts of PIR but little detail on how PIR is conceptualised and operationalised, how context and focus of a study affects PIR, and if the impact of PIR has an effect on research outcomes. This proposed study by considering different approaches to public involvement in a range of research settings and topic areas, will show how PIR can influence the research process and ultimately the dissemination and implementation of findings. commissioning of services and further research. It asks if there is a minimum level of involvement required to achieve certain outcomes. This is important to know in order to maximise the benefits of PIR within the resources available. The study will include a diverse range of PIR and therefore an economic evaluation would not be possible. However, the research will give an indication of resource use, cost and infrastructure which can then inform subsequent economic evaluations of specific PIR interventions.

3 Aims

Public involvement in research can improve the relevance, external validity and accessibility of findings for those most likely to benefit. There is a need for studies that can discriminate between the outcomes of different types and models of PIR, and the processes and context within which successful PIR is conducted. This is crucial not only for designing appropriate strategies for PIR, but also for assessing whether particular forms of PIR that are effective in one research setting are transferable (Craig et al. 2008). We also need to understand how public involvement in research can become an embedded feature (Howe et al. 2006) of the research process and environment rather than just superficially adopted or, indeed, rejected (May et al. 2007).

The study objectives are to:

- 1. Determine the variation in types and extent of public involvement in funded research in the areas of diabetes, arthritis, cystic fibrosis, dementia, public health and learning disabilities.
- 2. Describe key processes and mechanisms of public involvement in research.
- 3. Critically analyse the contextual and temporal dynamics of public involvement in research.
- 4. Explore the experience of public involvement in research for the researchers and members of public involved.
- 5. Assess the mechanisms which contribute to public involvement being routinely incorporated in the research process.
- 6. Evaluate the impact of public involvement on research processes and outcomes.
- 7. Identify barriers and enablers to effective public involvement in research.

4 Research design

Public involvement in research is a complex phenomenon, which needs a method of enquiry capable of capturing the interplay between outcomes, processes and the context in which it is conducted (Lilford et al. 2010, Campbell et al. 2007). The research team has extensive experience of complex evaluations and drawing on previous experience the research will therefore use a realist evaluation approach (Pawson 2002a, Pawson 2002b)

to investigate what type of public involvement provides what kind of outcome in relation to different types of research and settings. An overarching critical realist framework (Bhaskar 1978, Bhaskar 1986, Bhaskar 1989) will focus on the mechanisms embedded within an intervention such as PIR, facilitating an understanding of outcomes that may or may not occur depending on how they are triggered, blocked or modified (Kontos and Poland 2009, Connelly 2007). Realist evaluation (Pawson and Tilley 1997) draws upon this perspective and will be used to structure the research design. This requires robust mixed method data collection to collect sufficient information on the context (the setting and focus of the research), processes (type of involvement and formal support processes), structure and agency (organisational structures such as PIR frameworks and actions of stakeholders including researchers and lay representatives) within each case.

To demonstrate what elements of PIR influence research outcomes regardless of setting, those that are context specific, and what different approaches can and cannot achieve, we have selected six exemplar areas that by their focus and research tradition capture the full continuum of PIR. These are:

- 1. Cystic fibrosis. A life limiting condition that affects children and younger adults. Services are located within secondary care and specialist centres. There is a strong current laboratory based research focus on gene therapy. Compared to the other topic areas there is less of a history of PI with particular challenges in recruiting children and younger people.
- 2. Diabetes. Characterised by a clear clinical diagnosis, an emphasis on selfmanagement and lifestyle change. Affects people across the life span and services are predominantly delivered in primary care. PI well established particularly through powerful patient organisations.
- **3. Arthritis.** Occurs through the life span but predominantly in older people. A range of treatments in a range of settings with an emphasis on preventing further deterioration. A strong patient organisation and recent history of involvement in research that has informed the development of Expert Patient Programmes.
- 4. Dementia. A condition of later life with a limited life expectancy. Characteristics that can shape PIR include the unclear trajectory of the disease, the stigmatising nature of the condition, and reduced mental capacity, and a predominantly older person population within a primary care setting. There is a well established history of PI in the identification of research priorities in the Alzheimer's Society Quality Research in Dementia Network and an increasing recognition of developing research that is inclusive for this population.
- **5.** Learning disabilities. Widely varying conditions marking out a marginalised group in terms of health care delivery and health research. Despite the challenges of making research accessible for this group there is a well established history of PI, and well-developed theoretical and policy frameworks that inform policy, practice and research.
- 6. Public Health. Includes participants across the life span who do not see themselves as service users. May include community interventions and user-led projects in a variety of settings, but faces challenges in PI particularly in harder to reach groups.

5 Method

Utilising a mixed method approach, the study will be conducted in three stages.

5.1 Stage 1: National scoping of studies

To address objective 1 a national scoping of studies within the 6 exemplar areas will be undertaken of studies currently funded or completed within the last 2 years.

Sample: Current studies or those completed in the last 2 years in the 6 exemplar areas being undertaken in England. To ensure relevance to the NHS and scientific robustness, studies will be limited to those registered with the UK Clinical Research Network (UKCRN) portfolio, excluding commercially funded studies.

Data collection: Studies will be identified using the "grant look-up tool" on the UK PubMed Central database (UKPMC). Additionally, studies that have been completed in the last 2 years will be included within the scoping. Details of each study will be electronically searched via funding body databases. Relevant documentation such as reports, abstracts and protocols will be reviewed for the type of research (for example, laboratory based or qualitative), and any evidence of the nature and extent of PI. Where information is not available electronically the funding body will be contacted and requested to provide further relevant details of the study. Variations in PI will be mapped against the type of research, topic area and funding body. Drawing on the conceptual framework of Oliver et al (2008) and the research team member's recently completed systematic review (Brett et al. 2010) a scoping framework will be used to assess the stages of the research at which PIR took place, whether involvement was of lay groups or lay individuals and where it was located on the continuum of PI from user-led to minimal PIR. We will also assess evidence of the "architecture of involvement" (Brett et al. 2010); the processes needed to enable PIR. These processes would include a budget for PIR, defined roles for lay people, training and support, and means of communication between researchers and lay people. This will be used to evidence the range of resources supporting PIR.

Stage 2: Survey of lead researchers

Objectives 2, 3 and 6 will be addressed by conducting a survey of lead investigators. Informed by the findings of Stage 1, and in collaboration with Comprehensive Local Clinical Research Networks (CLRN) the survey will be conducted in four regions of England. These regions have been purposively selected to ensure maximum variation and will provide the test-bed for Stage 3.

Sample:

- **North East.** Major research hub located at Newcastle, historically an industrialised region with the associated impact on socioeconomic factors.
- **London.** Heavily clustered with a number of research centres, relatively high population from black and minority ethnic groups.

- **East of England.** Moderate number of research centres, diverse populations, established PI networks and organisations.
- **South West.** Relatively small number of research centres, relatively dispersed population in a mainly non-industrialised and rural setting.

The survey will be electronically distributed to up to 300 lead investigators across the four diverse regions.

Data collection: Drawing on the findings of the PIRICOM study (Brett et al. 2010), a validated on-line survey tool (e.g. http://www.surveymonkey.com/) has been designed to assess how PI is operationalised and the perceived impact on each study. While the PIRICOM study found little theoretical evidence of conceptualising PI, there has been some work to develop a consensus on the principles and indicators of successful PI (Boote et al. 2006) which has been used to underpin the survey design. The research team have used on-line survey tools before and their previous experience suggests that good response rates are achieved when the survey remains focused and takes no longer than 15 minutes to complete and rapid feedback is promised to participants. Participants will receive a summary of findings within a month of completion and can then compare their practice or experience with the overall findings. There will be close working with the appropriate CLRN, speciality networks and local speciality groups (LSG) to publicise and disseminate information about the study. Results from the survey will be compared to the national scoping exercise in Stage 1. The survey will be used as one of the ways to identify research teams who would be interested in taking part in Stage 3.

Stage 3: Case studies

Objectives 2, 3, 4, 5, 6 and 7 will be addressed through in-depth case studies. Stages 1 and 2 will provide a contextual backdrop and findings from these stages will inform on what is recognised as PIR in current and recent research. Stage 3 will deliver an in-depth realist evaluation of the context, mechanisms and outcomes in particular research settings and will increase understanding of at what points PIR has the most impact and effect on outcomes.

Sample: To ensure typicality and sufficient variation across; topic areas, types of research and geographical region, a sampling frame (figure 1) developed from the previous stages will be used to purposively select up to 20 case studies where the case is a single research study. This will enable maximum variation but also allows for comparison within and between region, topic area and type of research.

Figure 1: Sampling frame

| Type of | Topic area | | | | | | | | | | | | | |
|---------------|------------|----|----------|--------|----|------------|------|----|-----|------|----|----|--|--|
| research | Arth | CF | Dem | Diab | LD | PH | Arth | CF | Dem | Diab | LD | PH | | |
| Lab based | | | | | | | | | | | | | | |
| I T | | | | | | | | | | | | | | |
| | | | North | East | | London | | | | | | | | |
| ↓ | | | | | | | | | | | | | | |
| Users as | | | | | | | | | | | | | | |
| CO- | | | | | | | | | | | | | | |
| researchers | | | | | | | | | | | | | | |
| Lab based | | | | | | | | | | | | | | |
| 1 | | | | | | | | | | | | | | |
| | | E | ast of I | Englan | d | South West | | | | | | | | |
| | | | | J - | | | | | | | | | | |
| V Vsers as | | | | | | | | | | | | | | |
| co- | | | | | | | | | | | | | | |
| researchers | | | | | | | | | | | | | | |

Recruitment of case studies: To ensure a range of studies that vary in the stage of research a number of recruitment strategies will be employed:

- a. Potential studies will be identified from the survey
- b. Suitable early stage studies that have been awarded funding but are preadoption on the UKCRN portfolio will be identified by local Research Design Services (RDS), relevant charitable funding organisations from the AMRC, and by networks such as the PCRN from their futures list. The RDS, AMRC organisations and local research networks such as the PCRN will send out information about the RAPPORT study and investigators interested in participating will be asked to contact the RAPPORT study team.

Data collection: Data will be collected to inform the three stages of realist enquiry; context, generative mechanisms, and outcomes (Connelly 2007).

1. Documentary analysis: Key documents from each project will be analysed (Abbott et al. 2004) to situate the project historically and capture the temporal dynamics of PIR at the micro (project), meso (host organisation) and macro (funding body) levels. Documents will include those pertaining to PI policy, structures and support mechanisms (e.g. training) in the host (e.g. higher education institution) and funding organisations. Project team and advisory/steering group meeting notes or minutes will be requested from participating case studies and will add to the documentation collected in Stage 1. Other relevant documents may include, for example, participant information sheets.

2. Semi-structured interviews: Telephone and face to face interviews will be conducted with up to 6 key informants per case study. Depending on the study this will include the PIR members, lead/senior researcher, steering/project management group member, clinical partners and link person in the funding organisation. An interview guide will be used drawing on normalization process theory (NPT) (May et al. 2007). NPT is an action theory which seeks to examine patterns of social action and using it as a framework

will focus the research on mechanisms and associated impact and outcomes of PIR. The ESRC-funded web-based NPT toolkit will be used (May et al. 2010) to develop "radar plots" that will provide a visual identification of issues in the implementation of PI, enabling comparison between case study sites and in-depth analysis of key themes running through all stages of this proposal. In the case of children, and people with learning disabilities involved in studies, data collection tools have been reviewed and modified in collaboration with a reference group of people with learning disabilities, and a reference group of younger people with cystic fibrosis and their parents.

3. Tracking: Ongoing studies will be tracked over an 18-month period to identify public involvement processes. In negotiation with the study team this will involve a regular focused telephone interview with the lead investigator or other nominated member of the research team. The frequency of this contact will depend on study characteristics but it is anticipated that it will occur on average every 12 weeks. At 6 and 18 months the NPT radar plot will be re-evaluated to capture any changes in PIR processes.

6 Sample

Inclusion & exclusion criteria

We will include researchers and service users/public who:

- Are involved in a study eligible for adoption on the UKCRN portfolio in one of the six exemplar areas.
- Are 13 years old and over
- Gives informed consent

We will exclude researchers and service users/public who:

- Are not involved in a study eligible for adoption on the UKCRN portfolio in one of the six exemplar areas.
- Are under the age of 13.
- Does not give informed consent.

Survey

We will survey up to 300 researchers in stage 2.

Interview

We will interview up to 6 informants in each of the 20 case study sites in stage 3 (up to 120 participants).

7. Analysis

Analysis will be informed by the research questions and realist evaluation, with methodological triangulation occurring during analysis and interpretation of results (O'Cathain et al. 2010). The focus of the survey in Stage 2 is to describe researchers' experiences and perceptions of positive and negative outcomes of PIR, and benefits and challenges of PIR for researchers. The focus of analysis in this stage will therefore be the use of summary statistics alongside qualitative analysis of open text responses. Using an electronic survey tool will enable rapid access to data that can be readily transferred to SPSS for analysis. This analysis will be mapped against the results of the scoping in Stage 1 to identify any recurring patterns within and between types of research, stage in research process where PIR occurred, and topic area.

Data from the case studies in Stage 3 will be brought together in two tranches of analysis: within-case and cross case analysis. This case analysis, and the scoping and survey results will together establish the outcomes of PIR, identify generative mechanisms that enable or hinder PIR outcomes, and key contextual factors that impact on PIR outcomes. Qualitative data analysis will use NPT as an analytical framework to assess coherence (how people make sense of PIR), cognitive participation (how people develop and sustain PIR), collective action (how PIR is operated) and reflexive monitoring (how people assess the affect of PIR on them)(May et al. 2010). Thematic content analysis will identify key themes and common experiences which will first be site-specific and then used to make cross case comparisons. This will establish how different contexts (e.g. topic area, type of research and setting) affect processes (e.g. training and support), mechanisms (e.g. relationships and communication), and outcomes of PIR such as evidence of changes/responsiveness to PIR input, and impact on dissemination.

8 Ethical issues

It is not anticipated that any major ethical issues will emerge from this project. However we are aware that we may be including younger people, people with learning disabilities and users of dementia services. There may also be sensitivities in discussing experiences of a project with the potential to expose bad practice and misuse of PIR. The team is skilled in working in sensitive areas and with these groups.

Written, informed consent will be taken from all participants participating in interviews in stage 3. In the case of any younger person or person with a learning disability who are undertaking PIR, it will be important to have specific strategies for reinforcing messages concerning informed consent and the parameters of confidentiality, including the right to withdraw at any point. In particular we will agree a form of words or action they can use if they wish to stop the interview. The research team are experienced in conducting this kind of research with these particular groups.

9 Public involvement

Members of the public have been and will be involved in all stages of the research. Four members of the University of Hertfordshire Public Involvement in Research Group (PIRG) submitted initial ideas for the research proposal. Discussions at the regular PIRG meeting also fed into the development stage. The four PIRG members were involved in regular email and telephone contact as part of the outline proposal development team. Their contribution has actively shaped and informed the proposal design. Two research team members are members of the PIRG and actively contributed to the development of the full proposal which was also discussed at regular PIRG meetings. A parent and child with cystic fibrosis and a Learning Disabilities service user group advised on particular issues to take into account when working with these groups and have agreed to be part of a project reference group. Supported by the research team, the two lay research team members and a parent of a child with cystic fibrosis will act as co-researchers specifically undertaking interviews in Stage 3 and contributing to data analysis. Training will be given for this and support will be available as

needed. In addition, two members of the Norfolk Patient and Public Involvement in Research (PPIRes) group and a representative from the Royal College of General Practitioners PPI group will be on the advisory group and so continue to inform the study design. As research team and management team participants, members of the public will be actively involved in shaping the final report and disseminating findings. It is important that the impact of PIR within this research is recorded and PIR processes, actions and impact have and will continue to be recorded in detail through the course of the project.

10 Dissemination of findings

Outputs from the research will be aimed at three communities.

- Individual researchers and members of the public/users involved in research. One of the main outputs from the research will be a checklist for researchers and the public of structures and practices that can generate mechanisms leading to beneficial PIR i.e. which has a positive impact on research. The checklist will be structured using the NPT toolkit (May et al. 2010) that identifies the prerequisites for effective implementation. This toolkit has been developed and tested by a team of international researchers to provide a robust framework for evaluating the implementation of complex interventions, and has been used previously to explore the implementation of complex interventions including telemedicine(Finch et al. 2007) and the work of organising and managing chronic illness(May 2009).
- 2. Wider research community. The research team have established links with a wide range of researchers working in the same field. Dr Katherine Froggatt (University of Lancaster), co-applicant on a MRC funded systematic review and development of a user involvement impact assessment tool, has agreed to act as a collaborative link between the projects. This will ensure mutual learning and synergy between the 2 projects. The team have active involvement and input to a number of networks and organisations including CLRN and PCRN, Age and Aging Local Speciality Group (LSG), Health Service Research LSG, DENDRON research network and Alzheimer's Society, Royal College of General Practitioners, Society of Academic Primary Care, Community Practitioner and Health Visitor Association. These links with a broad range of research communities will be utilised to build on concurrent research and ensure wide dissemination.

3. Research policy makers and funding bodies. The findings of this research will be of particular use to INVOLVE in monitoring and evaluating policy dissemination and implementation of PIR. Funding bodies such as the NIHR and AMRC will also be able to draw on the findings to inform policy and practice.

At the end of the project dissemination seminars will be run in all 4 regions. Materials and presentation style will be adapted for children and people with learning disabilities as needed.

11 Project Advisory Group

The project will also be supported by an advisory group who will meet six monthly. Professor Mike Kelly (Director, Public Health Excellence Centre, National Institute for Health and Clinical Excellence), Professor Gurch Randhawa (Professor of Diversity in Public Health and Director of the Institute for Health Research, University of Bedfordshire), Professor Carl May (Professor of Healthcare Innovation, University of Southampton), Professor Fiona Brooks (Head of Child & Adolescent Health Research, University of Hertfordshire), Dr Katherine Froggatt (Head of Health Research, Lancaster University), Karen Inns (NCRN Consumer Involvement Lead) and Dr Jackie Ord (Learning Disabilities Research and Development Manager, NHS North Essex) have already agreed to be part of the advisory group. We will also invite representatives from the Cystic Fibrosis Trust, Diabetes UK, Arthritis Research UK, Alzheimer's Society, and MENCAP to be part of the group.

12 Flowchart



| | May 2011 | Jun | | Jul | Aug | Sep * | Oct | Nov | Dec | Dec Jan 2012 | | | Feb Mar | | Apr | May Jun Jul Aug | | Aug | Sep | Oct | | |
|---|-------------|-------------|-----|-----|-----|----------|----------|------|-----|-----------------|-----|-----|---------|--------------------|-----|--|------------|------------|-------------|------------|------|--|
| Completion of Protocol & Information sheets | 5 | | | | | | | | | | | | | | | | | | | | | |
| REC submission | | | s | sub | | | approval | | | | | | | | | | | | | | | |
| Scoping of studies | | | | | | | | | | | | | | | | | | | | | | |
| Face to face team meetings | | | | | | | | | | | | | | | | | | | | | | |
| Reference groups | 1 | | | | | | | 2 | | | | | | | | | 3 | | | | | |
| Refinement of | | | | | | | | | | | | | | | | | | | | | | |
| Survey of lead | | | | | | | | | | | | | | | | | | | | | | |
| researchers | | | | | | | | | | | | | | | | | | | | | | |
| studies | | | | | | | | | | | | | | | | | | | | | | |
| Research | | | | | | | | | | | | | | | | | | | | | | |
| Training of co- | | | | | | | | | | | | | | | | | | | | | | |
| researchers | | | | | | | | | | | | | | | | | | | | | | |
| | | | | | | | | | | | | | | | | | | | | | | |
| Data analysis | | | | | | | | | | | | | | | | | | | | | | |
| Advisory group meetings | | | | | | | | | | | | | | | | | | | | | | |
| Interim reports | | | | | | | | | | | | | | | | | | | | | | |
| No | ov Dec | Jan 2013 | Feb | Mar | Apr | Мау | Jun | July | Aug | Sep | Oct | Nov | Dec | Jan 2014 | Feb | | | | | | | |
| Case | | | | | | | | | | | | | | | | | | | | | | |
| Face to face | | | | | | | | | | | | | | | | Referer | nce gro | oup a | ctivity | | | |
| team | | | | | | | | | | | | | | | | 1 Advice on data collection tools | | | | | | |
| Data analysis | | | | | | | | | | | | | | | | 2 Discuss | emerging t | findings | from scop | ing | | |
| Reference | 4 | | | | | | 5 | | | | | | 6 | | | 3 Discuss emerging findings from survey | | | | | | |
| Advisory | | | | | | | | | | | | | | | | 4 5 0 5 | | | | | | |
| group meetings | | | | | | | | | | | | | | | | 4, 5, 6 Di | scuss eme | erging fir | ndings fror | n case stu | dies | |
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| Final report | | | | | | | | | | | | | | | | | | | | | | |

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