

**SDO Protocol - project ref:** 09/1801/1069

**Version:** 3

**Date:** 02/10/11

**Improving community health networks for people with severe mental illness: a case study investigation**

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**Sponsor**

Devon Primary Care Trust

**Funder**

SDO Programme

**NIHR Portfolio number**

**ISRCTN registration (if applicable)**

## **Improving community health networks for people with severe mental illness: a case study investigation**

**Summary:** People with severe mental illness (SMI) benefit from participation in creative and physical activities and from social inclusion in mainstream society. Primary and community care services provide some of these opportunities and others are derived from a person's wider social capital resources and social networks. This study assesses how organisations, practitioners and individual service users make or fail to make use of existing networks, how they create new ones and to what extent and under what circumstances these provide health benefits. It aims to identify best practice and produce guidance as to how networks of "health opportunities" for people with SMI can be initiated and developed in the community. Detailed case studies of the nature of networks, current practices and individual experiences, both service user and practitioner, will be generated through a five module research process in two contrasting sites (Hammersmith and Fulham in London and South Devon). The social networks of 150 service users will be investigated and analysed using UCINET software and 40 in-depth interviews, On-line organisation surveys will map the links between service providers. The emergent findings will be used to in a third site, Plymouth, through a series of action workshops to explore the wider applicability of the generated community health network model. Local delivery teams in each site will guide the project and the employment of service user researchers ensure active stakeholder involvement throughout. The resultant guidance will be of use to primary care and mental health services, local authorities and third sector organisations tasked by 'New Horizons' to work together for the well-being of people with mental illness.

### **1. Aims and objectives**

The study incorporates three specific objectives:

1. To map current community health networks utilised by people with severe mental illness to support their overall health and well-being
2. To identify organisational barriers and enablers in primary care and community health services to developing effective community health networks for people with severe mental illness
3. To provide recommendations for practitioner and organisational change to establish and support community health networks, which benefit people with severe mental illness

These will be explored by three main research questions:

1. How do people with SMI use their networks to support their health and well-being?
2. How do community-based practitioners and organisations support people with SMI to use their networks to effectively support their health and well-being?
3. How do primary care, community-based mental health providers and network organisations work together to develop more effective community health networks for people with SMI to improve their overall

health and well-being? What are the barriers and enablers to achieving this?

This study is not addressing interface issues between primary and secondary mental health care, instead it is collating best practice solutions and an in-depth understanding of how and to what extent organisations can link together with the wider social resources of people with SMI to better promote well-being opportunities to this group. This information will contribute to the Department of Health's (DH) ongoing commitment to improve services for people with SMI leading to better outcomes for them and their families (DH: 2006a, 2009). It will also provide practical guidance to support the personalisation agenda (DH: 2008) by placing the person at the centre of efforts to encourage preventative and sustainable health behaviours through engaging directly with their networks. At a community practice and practitioner level this study will provide resources and guidance to assist staff decision making, providing people with SMI access to a wider range of health opportunities supported through more comprehensive organisational networks.

## **2. Background**

People with severe mental illness (SMI) access a range of different health, social care and third sector services to support their mental health needs. However there has been less of a focus on how resources are accessed. Social networks, form the focus of this study because of their potential to connect individuals and organisations in order to promote better engagement and support for people with SMI. We will explore these networks by asking about their health generating properties thus producing what we are terming the 'community health network', As Pescosolido states, *"Too often we have neglected to consider that what makes people's experience in the community and treatment systems 'success' or 'failure' are intimately tied to the kind of relationships forged and maintained in those contexts"* (2002, p.468). In recent years there has been increased recognition that services must provide a 'seamless' package of care (DH: 1995, 1999, 2009). Mental health service users want to be treated holistically by practitioners, emphasising the interplay between social, cultural, economic and medical determinates of health and illness. All statutory and third sector services working with people with SMI are tasked by 'New Horizons' to enhance wellbeing. Practitioners, as well as forming part of individuals' networks, have a role to facilitate the development of networks beyond the 'service world' of specialist mental health services. Primary care could lead the way by innovatively supporting new ways to achieve these goals, linking up networks across the community and innovating to promote better health and social inclusion outcomes.

### **2.1 Health and social inequalities**

There are currently vast health inequalities between mental health service users and the general population (Disability Rights Commission, 2006) and these inequalities can not be explained by mental health problems alone (Samele, 2004). The link between mental illness and poor physical health has long been established (Phelan et al., 2001, 2004, Osborn, 2001, Folsom et al., 2007). Most mental health problems are associated with an increased

mortality (Harris & Barraclough, 1998). However, service users have expressed concern about the quality of GP services for people with SMI, with surveys showing poor understanding of people's needs (Rethink, 2003). The delayed identification of physical illnesses which result increases the likelihood of conditions becoming chronic and requiring complex and costly NHS treatment (DH, 2006b). Health checks in general practice for people with SMI, linked to financial incentives through the Quality Outcomes Framework (QOF), are only one part of the solution.

In recent years, the study of social networks as both a concept and strategy for managing mental health problems overlaps with research into social exclusion (Webber and Huxley 2004), social inclusion (Sayce 2001; Morgan et al 2007) and social capital (McKenzie et al 2002; De Silva 2006). In the UK, there is official recognition of the particularly disadvantaged position of people with mental health problems using a range of indicators (SEU 2004). As mental well-being is associated with individual better social and economic outcomes (Friedli 2009), enhancing the access of people with SMI to social resources may make a contribution to narrowing social inequalities (Webber, 2008).

## **2.2 The role of networks**

The study of networks aims to understand the complexity and heterogeneity of interactions in order to explain differences in outcomes for individuals, groups and organisations (Borgatti et al, 2009). It is underpinned by theories to understand the importance of relationships (flows, relations interactions) and structures (position, cohesion, connectedness, power and centrality). In his classic text Mitchell (1969) defined a social network as: "a specific set of linkages among a defined set of persons, with the additional property that the characteristics of these linkages as a whole may be used to interpret the social behaviour of the persons involved". Social relationships, interactions and organisational links form the networks that are important sources of support for people with SMI, impacting upon both physical and mental health (Berkman, 1995). They provide 'opportunity structures' for people with disability to manage relationships and social supports (Forrester-Jones et al., 2006) but evidence about the effect of features of social networks, such as size, density and frequency of contact, on mental health, is not consistent (Lin and Peek, 1999).

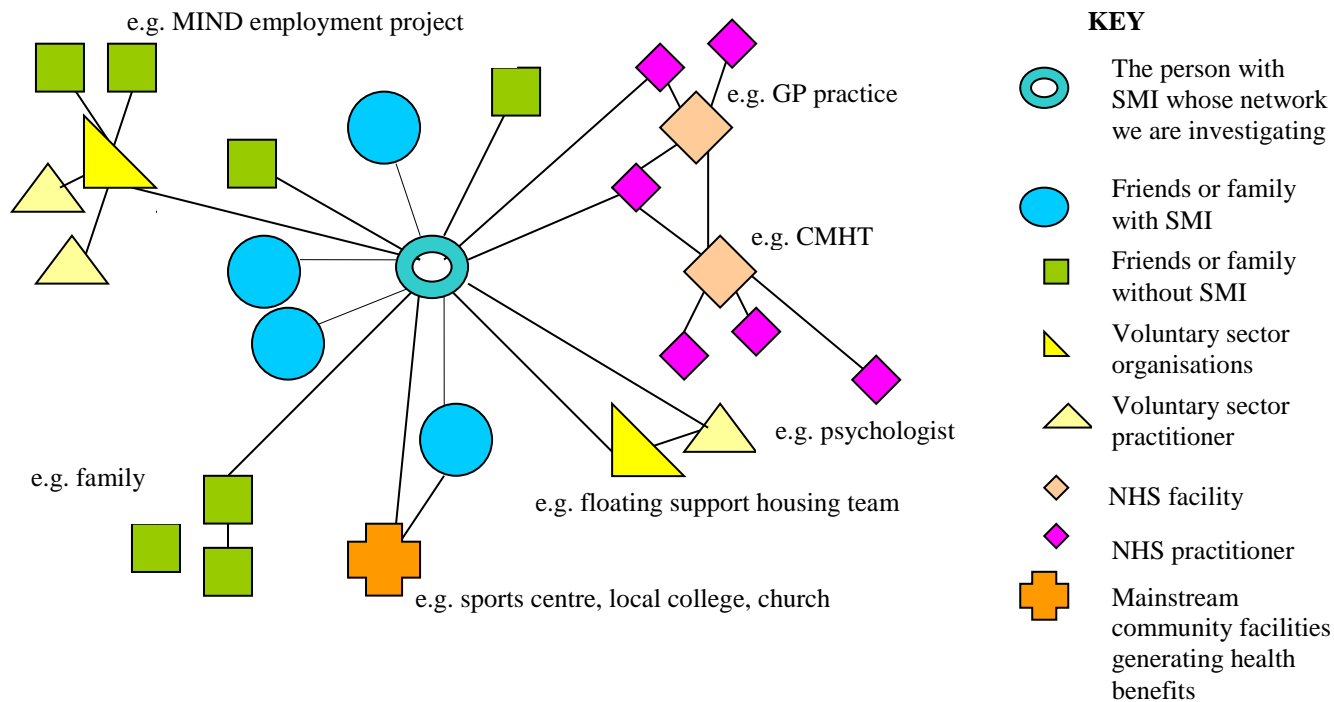
A network method allows a study of the complex relationships of people who are living with SMI. The notions of community, solidarity, inclusion, reciprocity, trust, boundary work are all relevant in defining a network form. In this study we are using the term *community health networks* rather than social networks in order to emphasise the ability of a network to generate health opportunities. This term provides an analytical framework to describe both the linkages between *people* (their role and quality of relationships – bonding, bridging and linking), *organisations* and *wider community resources* (such as virtual contacts or use of open spaces) and also the properties that make up the health opportunities on offer to people with SMI. This is a deliberately broad definition which will help identify the relevant networks and flow of resources which span traditional health services as well as community facilities and

informal resources such as family and friends. In effect each individual has a network which includes links to other individuals (friends, practitioners) and also to organisations or institutions (health or leisure centre). A particular concern for this study is how individuals' different social resources – manifested as specific relationships – are joined up and interlink with organisational networks (often mediated by individual practitioners) to deliver improved health outcomes. Figure 1 depicts the network of one hypothetical individual with SMI. The study will use a network methodology to explore health benefits generated and or lost across the network, network connectedness, nature and quality of relationships, health and social outcomes, and productivity across the network to assess how they might be improved.

The concept of social capital can contribute to our understanding of how social networks facilitate or hinder individuals' or groups' access to resources from other individuals, groups or organisations. Social capital is concerned with the structure and resourcefulness of the network in terms of emotional, instrumental and informational assistance (Song and Lin, 2009: 151). Lin (2001) suggests that individuals can anticipate returns from their investment in social capital through different mechanisms, which may improve their mental well being. Social capital research in the tradition of Putnam (1993) makes distinctions between different types of social relationships or interactions: 'bonding' (intragroup relationships, e.g. with families and friends), 'bridging' (intergroup relationships, e.g. with mainstream community facilities) and 'linking' (formal or institutionalized interactions, e.g. with traditional health and social care services) (Derose and Varda, 2009; Szreter and Woolcock, 2004). These distinctions may facilitate our understanding of how community health networks support people with SMI and we use them as a framework in this proposal.

Network mapping is complicated. Experiential maps and perceptions are in constant flux, particularly for people with SMI, and community health networks are also dynamic and changing. Equally we acknowledge that objective mapping of people's connections may hold a risk of normative judgements being made at the individual level about 'good' and 'bad' networks; we propose instead to utilise the individual with SMI's perception of benefit in our analysis of what makes an optimal network. We will use a layered approach to understanding their networks building on information about contacts and linkages, to understanding the health generating properties of the 'social network'. This will simplify and focus the task making the process manageable for people with SMI.

**Figure one: A community health network for one person with SMI**



### 2.3 Health benefits in networks

Research has shown the potential benefits for people with SMI of accessing wider health networks (Bird, 2000) including community exercise therapy (Daley, 2002), smoking cessation programmes (Addington et al., 1998) and health promotion networks such as the ‘Lets Get Physical’ programme in Plymouth (Byng, 2007). By facilitating relationships and trust between health care providers and marginalised people, community organisations can improve access to services. In particular, close collaboration between providers and community organisations (linking ties) can offer protection from potential discrimination and better accountability for treatment quality (Derose, Duan and Fox, 2002). Focusing on a networks approach to understand holistic health and social needs is particularly important for people with mental health problems – whose health require attention to the social as well as the medical. Social approaches are rarely used formally in primary care despite wide recognition of their importance and a high level of support for social approaches to mental health care: “Employment, housing and a strong social network are as important to a person’s mental health as the treatment they receive” (Appleby, 2007).

In summary, a networks’ perspective will ensure informal resources (including family support, online communities and self management) are mapped alongside statutory supports (including primary, secondary mental health and social care) and mainstream opportunities (e.g. leisure, sport, education), to provide a fuller view of how agencies and individuals can better interconnect to improve well-being (mental, physical and social).

### 2.3 NHS policy changes

Primary care practitioners and those in service users’ wider health networks are an important part of recovery pathways for people with SMI. The great majority (90%) of people with SMI are seen in primary care, with a GP

consultation rate of 13-14 times per year compared to 3-4 for the general population (DH, 2006b). Recent changes in health policy with regard to CPA may leave many more people discharged from secondary providers to primary care services. However, there has been little research to date understanding how current health structures enable or hinder health seeking behaviour of people with SMI. The role of primary and community health services in the development of networks of support for people with SMI is currently uncharted.

The policy landscape shaping the provision of health and social care is changing. In recent years there has been a drive toward empowering the individual service user to have greater influence in decisions governing their care and treatment. This includes the introduction of CPA care planning and extends to the current personalisation agenda with the piloting of individual budgets (IBSEN, 2008). The Department of Health describes how: “every person who receives support, whether provided by statutory services or funded by themselves, will have choice and control over the shape of that support in all care settings” (DH, 2008). This vision is reinforced in the New Horizons strategy (DH, 2009). To make the most of this policy shift, people with SMI need to be able to access a wide range of resources in the community. Through network mapping this project will provide the NHS and social care with a clear understanding of how organisations and individuals can interconnect to achieve better outcomes for people with SMI. It will identify network areas to develop, between individuals, individuals and organisations, and between different organisations as well.

### **3. Need**

This study is required because currently morbidity levels for people with SMI are unacceptably high, and the life expectancy gap between people with SMI and general population that is not closing (Saha and McGrath, 2007). We know people with SMI die on average 10 years younger than the general population (DRC, 2006). Health inequalities in terms of rates of heart disease, stroke, obesity, diabetes are all linked to SMI (Brown, 1997; DH, 2006a). Alongside statistics for poor physical health are data revealing high levels of stigma and discrimination, poor social inclusion and poverty among people with SMI (Thorncroft et al 2009). Despite the impact of mental illness on service users and their families, there is a scarcity of easy to implement solutions to tackle health inequalities for this vulnerable population. We will generate highly useful data of *long lasting relevance* because government policy continues to encourage the integration of service provision and the social inclusion of marginalised groups. In support of the wider personalisation agenda, our study will contribute to developing strategies for more effective engagement of people’s different social resources in organisational approaches to promote health and wellbeing. We will identify successful ways of working and encourage uptake of these solutions. Our study links to the SDO objectives of developing an evidence base on the provision of primary and secondary community health services and parallel programmes concerned with access to health services and integrated health services. At the heart of the project are community organisations tasked to deliver services to people with SMI. We will show how these organisations can link together

more efficiently and work with individuals to achieve better outcomes for people with SMI and their families.

#### **4. Methods**

The whole research will include the following components:

**A. *Engagement and joint working in two sites***

**B. *Data Collection***

1. Literature and Policy review
2. Organisational: Semi-structured interviews with leads and stakeholders  
Survey of practitioner experiences
3. Individual: Structured interviews with individuals living with SMI  
Semi-structured in-depth interviews with

individuals with SMI

**C. *Analysis:***

1. Analysis of 1-3 above
2. Synthesis and development of recommendations

**D. *Explore applicability of findings in third site***

**E. *Dissemination***

##### **4.1 Research methodology**

A mixed methods framework has been chosen for this study within a case study design (Gerring, 2007; Yin, 2002). Two case studies will be produced analysing information collected using a range of different techniques. Adopting an integrated mixed-method design (Moran-Ellis et al. 2006) ensures that structural and organisational description of detailed network patterns can be analytically linked to in-depth insight into lived experiences and the negotiation of relationships (Csordas 1994, 2002). While quantitative methods provide insight into general patterns and connections, qualitative research into experience is essential in order to capture the messiness and the inherent contradictions that are the reality of daily life (Jackson 1996). The integrated approach allows findings from the different methods to be used as complementary within an overall interpretive analytic framework (Moran-Ellis et al. 2006). In order that the study produces information directly relevant to NHS management, we will include engagement and feedback elements across the study and explore the applicability of our findings in a third locality.

The case study approach situates the research within two specific environments subject to particular local organisations of healthcare delivery. The methodological rationale will be drawn from Pawson and Tilley's (1997) framework for realistic evaluation. This emphasises an understanding of mechanisms operating in specific contexts, which create outcomes. Particular attention is drawn to what is working for whom, according to the stakeholders involved. In our case, this approach will be applied to the two sites, generating conclusions about each, but also permitting comparisons to be made. Current challenges or solutions will be cross referred between sites to promote shared learning. The analytical method will, by reducing qualitative data into context-mechanism-outcome matrices and setting it beside quantitative findings, generate provisional theories about which mechanisms for promoting optimal



networks are more likely to be effective (Byng et al 2008). It will also allow inferences to be made about which contexts are important (or not) in promoting better outcomes. “Optimal” will be defined by service users perceptions rather than objective measures of well being. In addition, by subsequently involving a third site in the project, we will be able to assess whether the experiences emerging from the detailed case studies can be applied in another locality.

The two-year study will ensure that both organisational and individual level practices are captured in detail with timely feedback to NHS managers, practitioners and service user / carer stakeholders based upon stakeholder knowledge and experiences. The feedback mechanisms are central within the study design ensuring that information gathered can be clarified and shared regularly with key decision makers and service users, in an approach similar to action research methodology (Elsey and Lathlean 2006). Individuals’ networks will be considered using the following framework:

- Bonding: Personal contacts (friends, family)
- Bridging: Informal community groups (leisure, walking groups, self help groups)
- Linking: Statutory services (health and social care, primary care, community mental health, pharmacies); Third sector (mental health providers, other e.g. CAB, carer organisations); Other statutory (education, etc)

A final aspect of our methodology that needs highlighting is the employment of service user involvement researchers (IR). We will appoint two IRs per site to assist the research team with specific tasks such as running the engagement and feedback events locally, producing study materials that people with SMI will understand and benefit from and have an integral role in the analysis of module 3B data through a series of analysis workshops. The study will thus benefit from the expertise of people with lived experiences who are likely to be better able to identify and critically examine subtle points or differences that may make all the difference in the lives of individuals experiencing SMI (Beresford, 2003).

## **4.2 Research design**

### **4.2.1 Data collection framework**

There are five study components, organised in three modules, running in parallel across two sites:

1. Literature and policy review
2. Organisational:
  - a. Semi structured interviews with leads and stakeholders
  - b. Survey of current organisational practices and strategies to create community health networks
3. Individual:
  - a. Structured interviews with service users living with SMI
  - b. Semi-structured in-depth interviews with service users living with SMI

#### **4.2.2 Study sites**

The choice of the two main sites, one in Central London and the other a rural area, reflects geographical variation, differences in deprivation levels and service configurations. We anticipate that there will be differences in the structure, configuration and size of community health networks between these two sites. While the sites will not be representative of PCTs across England, they will enable us to look in detail at process mechanisms allowing analytic generalisations to be made (Yin, 2002). The health and social care partners in these sites are willing to engage with the study and are committed to make changes based upon study findings.

The first is Hammersmith and Fulham PCT, inner city London, which has fully integrated health and social service provision. There are 30 GP practices and the Quality Outcomes Framework (QOF) data for 2008/09 showed 1589 people out of 1754 (91%) on the SMI register had a health check in the 15 months previously. SMI prevalence in Hammersmith and Fulham PCT is 1%. The second site is NHS Devon (Devon PCT) with 107 GP practices. QOF 2008/09 showed 3376 people out of 4007 (84%) on the SMI register had a health check in the 15 months previously. We will work with a sub-sample of practices in South Devon covering a rural area with small towns, where care for people with SMI is also provided by the Devon Partnership Trust. South and West Devon is one of 4 localities in Devon and incorporates the access and wellbeing network which liaises with GPs and supports care for people with psychosis but discharged to primary care. SMI prevalence across Devon PCT is 0.7%. Our third site, where we will explore the applicability of study findings in a third context, is Plymouth, which is a unitary local authority with a co-located Primary Care Trust. NHS Plymouth commissions local health care and the provider arm includes specialist mental health services. There are 44 GP practices in Plymouth, QOF 2008/09 showed 1336 people out of 1887 (71%) on the SMI register had a health check in the 15 months previously. SMI prevalence in Plymouth PCT is 0.7%.

#### **4.2.3 Target population**

The study is focused upon people with SMI, defined broadly to include people with schizophrenia, schizo-affective disorder, other chronic psychosis, bi-polar disorder, but excluding personality disorder. This broad definition is selected to ground this study in a clinically relevant 'real world' population rather than a narrowly defined research population. We are interested in chronically ill people with SMI and therefore the study entry criteria will include those in contact with secondary services for at least one year or having ongoing mental health problems seen in primary care of at least two years duration. We are excluding personality disorder without psychosis because their needs differ and would constitute a project in its own right. Also these patients are not included on SMI registers held by primary care practices which we will use as our sampling framework.

### **4.3 Data collection**

#### **4.3.1 Module 1: Policy and literature review (months 1-6, 13-14, 21-22)**

The first module of the study (during months 1-6) will involve a review of relevant literature and policy documents. Policies will be scrutinized to ensure that this study is placed in context of the changes affecting primary and secondary community health care. The literature review will be conducted with the intention of establishing both additional assumptions and detailed sub-questions of relevance to this project. These assumptions and sub-questions can be conceptualised as a prototype model for how networks should operate. The model will be utilised to inform data collection, and provide a starting point for analysis in each subsequent module as empirical findings will confirm or call into question basic assumptions in the model and lead to incremental revisions. Local documents in the two study sites as well as national policy briefings will be identified systematically through on-line search engines and the engagement events and Advisory Network (AN) / Local Forums. Research papers will be identified using on-line search engines (e.g. medline, psych info) and detailed manual scrutiny of reference lists from identified papers. Authors will be contacted if necessary and we plan to utilise the membership of the AN and their networks of contacts to assist with this phase. During the final analysis of our study data, the literature will be updated, so that conclusions and recommendations from our study can be linked to evidence emerging elsewhere. This module will be led by the project coordinator with input from the two study research officers.

#### **4.3.2 Module 2A: Semi-structured interviews with leads and stakeholders (months 1-8)**

The aim of this module is to understand the broad context and specific operational working of community health networks for people with SMI in two study sites. In doing this we will begin to generate data in order to answer our 3 core study questions. Interviews with 12 participants per site (24 in total) will be carried out in the first few months of the project to gather contextual information on the organisation of services, and provision of support to people with SMI locally. The recruitment sample will be informed locally using a social capital framework (bonding, bridging, linking contacts). The interviews will seek to understand:

- How local organisations work with individuals to coordinate holistic service delivery to meet the needs of people with SMI in the community
- How service providers consider and make active use of the individual networks of people when determining their support and treatment needs
- How organisations work together as a network to ensure seamless care and promote additional well-being opportunities for people with SMI

An interview guide will be developed by the research team and interviews will be carried out by study research officers. Interviews will be audio-recorded and transcribed in full by the study research officers before undertaking a broad thematic analysis. This module will identify key organisations, particularly mainstream facilities not specifically designed for people with mental health problems, which may not be listed in local resource directories. Based on these data a list of local organisations will be included in the on-line survey (see below).

Towards the end of the study (from month 18) we will carry out a second series of interviews with stakeholders to feedback data from our quantitative analysis of both the organisation survey (module 2B) and individual network interviews (module 3A). These interviews will explore the findings from our analysis and generate ideas for new ways of working to address observed patterns in the networks. We again aim to interview 12 participants per site.

#### **4.3.3 Module 2B: Survey of organisations (months 7 – 17)**

The aim of module 2B is to collect a cross representation of practitioner views to understand:

- How well organisations are linked, with whom and in what ways, to support people with SMI
- How practitioners themselves seek to support people with SMI to generate opportunities to improve overall health and well-being
- The barriers and enabling influences to generating better organisational practices and better individual outcomes

#### *The sample*

A database of community resources for people with SMI will be compiled, and data from module 2A in South Devon and London, to provide a sampling framework for the survey. A sample of service leads of every local service related to mental health, physical health and social inclusion for people with SMI will be contacted (by letter or email) and invited to take part in an on-line survey, on behalf of their organisation. We will seek to include representation from the following community services (offering a mix of bridging and linking social capital):

- Secondary mental health services in the community: CMHTs, Assertive Outreach, Early Intervention, third sector services
- Primary care: practice nurses, GPs, primary care mental health team practitioners
- Community based health services: dentists, pharmacies, opticians, podiatrists, therapists
- Mainstream services supporting people with SMI access resources in local community that impact on health such as education, employment, recreation, arts and culture
- Third sector organisations: support groups, “think-tanks” and providers

Non-responders will be sent a reminder and followed up by researchers by email for their responses.

#### *Survey tool*

The on-line survey will be developed by the research team in consultation with local forum and the AN. It will be piloted with practitioners prior to use. Information gathered will specifically address:

- Links and relationships between organisations – e.g. participants will rate how strong their links are to a range of local organisations using a 5 point scale: 0= not heard of them, 1 = aware, 2= occasional contact, 3=regular contact, 4=shared protocols for referrals and joint working
- Benefits acquired from links

- Description of the services provided by organisation to people with SMI, and adaptations introduced to take account of specific needs of this group. We will include questions capturing the nature of the support or activity provided, allowing us analytically to ascertain whether the organisation in question mainly offers 'bridging' or 'linking' opportunities for people with SMI. We will invite participants to identify examples of practices that are working particularly well locally to support people with SMI develop community health networks
- Extent to which organisation makes efforts to cater for and reach out to people with SMI
- Attitudes towards increased partnership working and network activity locally
- Views on the most significant challenges for people SMI locally in building strong community health networks

#### *Analysis*

Quantitative data will be entered into SPSS for analysis. We will carry out descriptive statistical analysis on strength of ties data between organisations. Network analysis will be completed based on the type (bonding, bridging, linking) and strength of links between participating organisations, to show which organisations are central to active promotion of SMI wellbeing. Qualitative data will be coded for basic content and to describe local networking activities. We want to understand to what extent these organisations are aware and make use of each other in order to generate health opportunities to people with SMI.

#### **4.3.4 Module 3A: Individual structured network interviews (months 1 – 22)**

Aim: to produce community health network maps from a sample of service users who experience SMI representing pathways and opportunities used to improve their health based upon established social network methodologies.

We will recruit 75 people with SMI per site, providing a total of 150 participants. Each service user will be interviewed by a study researcher using assessment tools to map their networks. Information from the following domains will be collected:

- Participants' characteristics (e.g. demographic information, basic illness history, living arrangements) will be collected from participants. We will seek consent to access patient diagnosis from medical records.
- Warwick-Edinburgh Well-Being Scale (Stewart-Brown et al 2009) – short version – to provide current mental well-being status
- Dartmouth Function Coop Charts (Beaufait et al 1992) to provide current physical health status
- Networks mapped using the Name Generator and Resource Generator, adapted to detail health generating network properties. Three layers of information will be collected: map all network links – people, places and activities; assess benefits generated from links; for those links and contacts generating significant health benefits explore how they were created and assess more detailed properties

- Network experiences – we will ask 5 questions to each participant to capture: network activities generating greatest health benefits for individual; how organisations facilitate or discourage links; overall satisfaction with network properties to provide optimal health benefits

Two measures will be used to provide self report physical health status information and mental well-being status. These will also provide information to explore the association between network characteristics (size, structure, interaction, function) and objective health status (both physical and mental health). To measure participants' community health networks, we will use two related measures – the Name Generator (McCallister and Fischer, 1978) and the Resource Generator-UK (Webber and Huxley, 2007). Both will be adapted to capture detail specific to examining community health networks.

The name generator approach to gathering social network data is the most valid, reliable and frequently used tool for the collection of person-centred network data (Marsden, 1990). It has also been reliably used in populations of people with SMI (e.g. Clifton et al., 2007, Pernice-Duca, 2008). The Name Generator will be supplemented with a list of questions asking participants to name organisations that they are currently in contact with (e.g. primary health care centre, secondary community mental health services, social services, third sector organisations and community facilities) and the activities they do in particular places (art classes, walking, watching TV, socialising). Participants will be asked a series of name interpreter questions about each key health benefiting network member to elicit their connections with other network members or organisations. The individual will define what a 'key' benefit means and who this applies to across their network using a bespoke rating scale --2 to +2 (-2 very negative health impact to +2 very positive health impact). We will also assess health impact of places and activities in the network using the same scale.

The Resource Generator-UK asks participants whether or not they have access to 27 social resources within networks. The instrument has four internal domains – domestic, expert advice, personal skills and problem solving social resources – and is quick and easy to administer. Comparative data is available from primary care (Webber, 2008) and SMI (Dutt and Webber, in press, Murray et al., 2007) populations in addition to general population norms (Webber and Huxley, 2007). The instrument will be modified to assess a participant's access to resources via personal contacts (bonding), community facilities (bridging) and NHS primary or secondary care services and voluntary sector providers (linking). A new scale will also be developed and piloted to measure specific access to health, as opposed to social, resources in the community. The new scale has 16 items in the pilot. We will also include a measure of subjective value of each network link, whether bonding and bridging resources existed and whether 'linking' resources helped facilitate other links – thus capturing the components of the network created with the help of health and social care. The modified name generator and resource generators will be piloted with a small sample (n=5 from each site) to allow us to refine the questions and amend relationship categories of the resource generator, test for interview length and assess participant

burden. These measures will enable us to describe the structure of networks and the extent to which their network members are concentrated within the mental health system or linked to primary care service networks.

### *Sample size*

Our sample size is informed by a UK study of the social networks and needs of users of mental health day services (Catty et al., 2005). This study found users of a social services day centre had larger networks, but more needs, than users of a day hospital. In our study we will need to examine comparisons regarding a number of variables and so the sample size is pragmatic, based on realistic numbers (informed by the Catty study) which will be sufficient to find subtle differences in network properties against a range of other variables. A key evaluative principle will be to understand from participant's perspectives the extent to which the health benefits derived from their networks are optimal. For example, we hypothesise that individuals with social relationships with a higher proportion of people outside of the mental health system will perceive their network as bringing greater benefits because of increased opportunities for employment, leisure, social support and access to other valuable resources that can be gained through these wider connections. If we were to divide a sample of 150 people into two equal groups of those above and below the median of a measure of subjective value of their network, we have 86.5% power to detect a hypothesised difference of 10% in the proportion of an individual's network which is comprised of other mental health service users between the group who value these contacts less (mean proportion=40%, s.d.=20) and the group who value these contacts more (mean proportion=50%, sd.=20) at the 95% significance level. This power calculation was performed in Stata v.9.2 using the command: `sampsi 40 50, n1(75) sd1(20)`.

### *Sample selection and recruitment*

People with SMI in both study sites will be randomly selected from the QOF SMI registers of 8-15 GP practices per site. Target recruitment is 75 people per site. We will over sample by 500%, aiming for a 20% response rate. GPs will screen lists of potential patients to be approached, removing those assessed as 'at risk' on medical grounds. Ethical approval will be required and the process assisted by local research network staff – Mental Health Research Network and/or Primary Care Research Network . Invitation letters will be sent from the Practice to attend an interview appointment with the researcher at the practice; this is a process people are used to. If contact via Practice is unsuccessful, the named community team – early intervention, CMHT, assertive outreach – will be approached and follow-up recruitment attempted. The practice/network staff will make 2 attempts to contact each randomly selected participant, first by letter and secondly by follow-up phone call. Participants return an expression of interest form to the research team and full consent is collected at the interview.

### *Interviews*

People with SMI attending the interview will be provided with information, asked if they wish to consent and interviewed then or another time if they prefer. Interviews will be in a GP surgery or other agreed public space but not

in the service user's own home to protect both the service user and the researcher, by having staff on hand if either became distressed. Immediately prior to the interview the patient's named key worker or GP will be informed about imminent interview and asked to inform researcher of any relevant 'risk' information. It will also alert them that they will be contacted if the patient becomes distressed as a result of taking part in the study. All information will be recorded on data collection schedules, inputted by the research officer at a later date into Micro-soft access. It is anticipated that the interviews will last approximately two hours. They will be carried out by the study research officers, assisted by the project coordinator. Participants will be offered £20 per interview for taking part.

### *Analysis*

UCINET (Borgatti et al 1999) has been selected for the social network analysis as it is a comprehensive and widely used package capable of analysing both ego-centred and whole networks. It has been particularly widely used in the analysis of primary care and health networks (e.g. Fattore et al 2009, Scott et al 2005, Weeks et al 2002). It has been chosen in preference to other social network analysis tools because its diverse authorship, encompassing a range of mathematical and methodological expertise, ensures that the program can undertake multiple operations both proficiently and efficiently. Visualisations of networks will be undertaken using NetDraw, a program integrated within UCINET.

We will address a range of questions including:

1. What makes up the community health networks of people with SMI?

We will use standard social network analysis procedures in UCINET to calculate network properties (size and density); demographic composition (mean age, % gender, % ethnicity, % within community health network); role relationships (e.g. % kin, % non-mental health service users); type of contact (bonding, bridging, linking), ego-alter characteristics (mean closeness), network activity (frequency of contact) and perceived health benefits derived from network contacts. Data will be aggregated to case study site level to facilitate inter-site comparisons.

Using NetDraw, we will make visual representations of participant's networks in both study sites to facilitate comparison. We will superimpose this with the local organisations providing services to people with SMI obtained in modules 2A and 2B of the study. This novel approach will bring together ego networks and organisational structures to accurately depict the nature of health networks in the two study sites. To our knowledge, this has not been achieved before and will help us to fully understand the extent of 'bonding', 'bridging' and 'linking' social capital within community health networks of people with SMI.

2. What is the mix of formal and informal health care provision within people's network?

We are interested in who are providing health benefits – family, health professional and community resources. We will use the decomposition capability of UCINET to separate network contacts according to whether they



provide formal, informal or no health care benefits. This will be analysed by visualisation and by calculation of the properties of these sub-networks as above. This process will allow us to evaluate the extent to which networks facilitate the involvement of informal contacts in formal healthcare provision.

3. Do these networks differ in composition, range, size and density across sub-groups within this population (e.g. based upon gender, ethnicity, age, disability, level of need)?

We will use univariate statistics to compare sub-groups across all network and social resource measures. We will also conduct appropriate multivariate analysis to explore predictors of network size and other network properties

4. How do network strength and breadth relate to perceived benefit and well being (SWEMWBS and Dartmouth Coop)

We will conduct an exploratory multivariate analysis using perceived benefits of network contacts and well-being (SWEMWBS and Dartmouth Coop) as our outcomes. A sub-set of variables from those listed below (those showing significance on univariate analysis) will be used as our sample size is small. Network measures such as size and density; demographic composition (mean age, % gender, % ethnicity, % within community health network); role relationships (e.g. % kin, % non-mental health service users); ego-alter characteristics (mean closeness), network activity (frequency of contact) and source of network contacts would be entered sequentially into a regression model to identify which network characteristics are associated with perceived benefit of network and objective well being.

#### **4.3.5 Module 3B: Individual network semi-structured in-depth interviews (months 6-22)**

The aim is to deconstruct the concept of a community health network and unpack meaning for each participant so that we can understand the significance of different types of contact and barriers to health seeking behaviours, as well as the dynamic inherent in each network's configuration. We will determine how people with SMI have created and accessed their useful networks, and what actions of their own, or of others has contributed to the development of a network of health opportunities, thus furthering our understanding of the mechanisms at work in the community. This will inform future work by professional helpers and also indicate possible avenues for intervention research.

To supplement the detailed network data collected in 3A, we will interview 20 service users per site, providing a total of 40 in depth interviews with people with SMI. The data gathered in module 3A will provide a starting point for the interviews: in keeping with a realistic evaluation framework, the reasons behind either positive or negative network components will be explored in the interviews:

- How do identified social resources and relationships impact (positively as well as negatively) on the health and wellbeing of people with SMI?
- How do people with SMI actively make use of or access particular social resources within their network to support their health and well-being?

- How have the health and social care practitioners in their networks contributed to supporting the creation of wider beneficial networks?
- What kind of reciprocity exists and how does contributing to others influence wellbeing in terms of burden and benefit?
- How could practitioners reduce barriers and encourage growth of strong user centred networks in local communities?

#### *Sample selection and recruitment*

Participants for the qualitative interviews will be recruited directly from the structured network interviews in module 3A. Potential participants will be asked if they would like to continue for a further 30-45 minutes to answer some more detailed questions as follow-up. They will have the option to do this following a short break, or arrange a new appointment for the in-depth interview. This approach will give us an optimal response rate and allow the in-depth interview to benefit from the relationship already established between participant and researcher. In each site the first 10 participants will be a convenience sample based on time available and participants' expressed interest in taking part. The other half of the sample will be purposive and selected based on emerging findings to ensure inclusion of maximum variation both in terms of participants' profile (gender, ethnicity, living arrangements, disabilities: physical and mental health) and network composition (e.g. small vs. large, mostly professional vs. mostly personal). The research officer will have a list of prioritised factors to look out for in the profile and the first person interviewed during module 3A to meet these will be invited for the follow-up qualitative interview. The procedure is continued until the total of 20 in-depth interviews in each site has been reached. It is not anticipated that saturation will be achieved.

#### *Analysis*

The 40 interviews will be fully transcribed verbatim and be subject to thematic analysis by the research officers and involvement researchers. The in-depth data will allow a detailed examination of the subjective importance of individual relationships and how these fit into the wider structure of a network. It will be possible to explore how perceptions of different contact types (bonding, bridging, linking) relate to the role relationship, and the background for relationships forming in particular ways. It may, for example, be that some participants perceive their relationship with a health professional as having 'bonding' or friend-like qualities – the analysis will examine the background for this and any health benefits related. The following data analysis process will be followed. Ten interviews will be completed before analysis begins (major issues related to wording and flow rather than content will be addressed earlier as required). Then, research officers and service user involvement researchers will read through the first 10 interviews individually to familiarise themselves with key issues and through a workshop discussion develop an initial coding framework. At this stage the interview schedule may be modified to systematically address key findings emerging but not initially anticipated. Another 10 interviews will be carried out before a second analysis workshop is held with research officers and service user involvement researchers bringing coded transcripts to discuss. The original coding framework will be revised and refined to capture new emerging themes or to collate themes as required.

The analysis approach will address both communalities in the data and deviant cases that may challenge or contradict these. The qualitative data analysis software NVivo will be used to assist the management of data and facilitate systematic data examination.

#### **4.3.6 Data synthesis (months 21-24)**

We will bring together our data sources to provide a model of community health networks; how they work and how they provide health benefits to people with SMI. The analysis, incorporating qualitative and quantitative data, will be carried out across the two sites to develop the model. This will describe the multiple layers of connections and network qualities as well as revealing the complexity of individual experience. We will integrate this with the analysis in module 2 concerning organisational network resources. A realist driven evaluation approach will be used to explore the role and significance of different contact types and organisational resources available within different community network forms.

Synthesis of the results from each module is a critical process for ensuring that an integrated model, describing how networks can be developed to benefit people with SMI, is produced at the end of the research. The individual stages of data collection will inform each other in such a way that earlier stages provide information to shape the questions raised or sampling for later stages. Prior to this our literature review will have already developed a prototype model for how 'community health networks' can operate, whilst also incorporating key unanswered questions as to how organisations should operate and individuals (practitioners and people with SMI) might best behave to optimise the benefits.

Synthesis involves incorporating levels of detail from organisational practices down to individual interactions, emotions and behaviours. The data are multi-dimensional with each component explaining a part of a bigger picture that will be brought together within the analysis. Each of the two case studies provide an empirical framework for analytic integration by highlighting particular questions of local relevance that the data sources will contribute to from different perspectives. We will systematically review each of the components and levels of the prototype model and make revisions based on the evidence accrued in each site and from each module. Where possible the unanswered questions that arose in the prototype model will be addressed. Relevant qualitative data will be reduced into context-mechanism-outcome matrices and compared with quantitative data related to the same issue. The different data sources are likely to either be confirmatory (triangulation) or divergent with respect to specific issues; divergence may require further data analysis, bracketing or exclusion (Pluye et al 2009). In line with the integrated approach to multi-method analysis (Moran-Ellis et al. 2006) we will treat the multiple levels of information as supplementary within an interpretative framework, as different parts of a bigger picture, contributing to a more comprehensive understanding of the complex phenomenon being studied. The Local Advisory Network (LAN) plays an important role in assisting the research team bringing the different data pieces together to address local concerns and seek answers to specific issues of relevance to the community. Data analysis

workshops will be held with each LAN and include the service user involvement researchers to assist this integration. This will generate a local 'holistic picture' presented by each case study analysis. The research team will compare the two case studies to identify factors that may explain either communalities or differences specific to the local community health networks used by people with SMI in rural and urban settings. A practical guide to developing health optimising networks will be produced which will address theoretical and practice-related questions arising from the literature review work that feeds the study throughout.

#### **4.3.7 Assessing relevance of findings in third locality**

Synthesized data from our two case study sites will be presented in a third locality – Plymouth – to both practitioners and service users. The aim is to assess how transferable the practical recommendations are for a third locality, and how far experiences described in the community health network model apply to individuals and organisations elsewhere. We will use this phase to assist us in producing our practice guidance tools and resources. It is important that Plymouth service users and practitioners are aware of the study from the beginning, and thus engagement activities in Devon will involve them. The first Plymouth based event is planned for month 10 in the project to engage and share information about the study. In the final months of the study (months 20-23) action workshops will be held in Plymouth (4 in total) to assess and develop the relevance and local interpretation of findings from Hammersmith and Fulham PCT and NHS Devon for service users and practitioners in Plymouth. The LAN will assist with developing the format of the events, but we anticipate they will be informative as well as consultative. These sessions will be co-facilitated by the service user involvement researchers and study research officers; they will also be supported by PenCLAHRC which has resources to support and evaluate translation of research into practice.

#### **4.4 Engagement, feedback and change (months 1 – 24)**

The study's feedback elements consist of events and e-newsletters. These will be planned with the LAN and provide opportunities to communicate with stakeholder throughout the life of the programme. This is important, even during a relatively short (24 months) research project, in order to make NHS managers aware of emerging findings.

##### **4.4.1 Engagement**

A key component of the study will be engagement events, at the start to ensure local organisations are on board with the study. The aim is to both make local service providers aware of the study and to collect information to develop a database of current resources – both directly health related and associated activities such as assisted employment programmes, volunteer placement schemes, walking groups, environmental projects. Each event will be action orientated, with an exchange of information between researchers and stakeholders, discussion about barriers and facilitators, followed by decisions about how to develop the network further. These discussions will be recorded and utilised as data. Information gathered during this engagement

phase will also be used to develop a recruitment framework for the practitioner survey (module 2B).

#### **4.4.2 Feedback**

Two feedback mechanisms will operate. Firstly, three newsletters will be produced by the two service user involvement researchers on each site alongside the research officer. These will highlight case studies of positive networking practices as well as study progress updates. Secondly, dissemination workshops will run in each site. Based on the findings from modules one to three of the study the research team and LAN will put together a set of targeted recommendations for the two PCTs which will be presented to a half-day dissemination workshop in each study site. The workshops will include presentations from the study team, local service users and local managers. The workshop would allow time to discuss and agree these initiatives. We anticipate the research will highlight some practical changes to improve practice:

- Dissemination and awareness raising of network organisations and opportunities
- 'Shadowing' of workers between organisations
- Shared events and joint activities for people with SMI
- Registration drive to encourage people with SMI to register with a GP

A guide for service users will also be produced by the study team, led by the involvement researchers, outlining how to develop both individual and to promote comprehensive community wide networks. This will be disseminated through Rethink's extensive networks to service users, practitioners and commissioners across England. A second guide for service providers will also be produced including recommended actions for clinical and practical work with individuals, and practical steps that organisations within the networks can take. We will work with Trusts and other networks to disseminate these findings widely, using new technology including blogs and social networking if recommended by our LAN and advisory group.

#### **5. Contribution to collective research effort**

The dissemination activities from this study are in two component parts. Firstly there will be ongoing feedback throughout the course of the study within the case study sites. Mechanisms for organising knowledge mobilisation across the NHS and to stakeholder groups include;

- E-newsletters coordinated by the local involvement researchers.
- Engagement meetings and feedback sessions to groups of staff at relevant meetings and events held over the two years.
- The active engagement of senior NHS managers within the study as members of the local delivery team.

Secondly there will be specific activities and products at the end of the study, collating data from the entire project. The main knowledge outputs will be:

- Final report accessible on NIHR SDO website

- A guide for mental health service users on developing community networks, developed in close consultation with local involvement researchers and LAN
- A practical guide for PCTs on setting up organisational networks
- Attendance at academic conferences to deliver papers from the study
- Peer review publications
- Articles in trade press such as Mental Health Today, Community Care and national press.
- We will work with Rethink Media and Campaigning teams to ensure that findings and recommendations are brought to the national political agenda. Furthermore, Rethink activists will work to promote findings and recommendations locally

## 6. Plan of investigation and timetable (amended Sept 2011)

| Month                 | Project management                                      | Engagement and feedback                                     | Module 1: Literature / policy Review                | Module 2: interviews and organisational survey               | Module 3: Quantitative and qualitative individual network interviews   |
|-----------------------|---|---|---|--|--|
| <b>Before project</b> | PMG<br>Recruit ROs<br>Set up AG<br>NRES                 | Submit R&D paperwork  | Draw up parameters for literature and policy review | Identify local practitioner and SU leads                     | Identify potential tools for cohort study.<br>Work with MHRN and PCRN to plan approach<br>Agree access to SMI register |
| <b>1: April 2011</b>  | PMG<br><i>RA starts in London</i>                       | PCRN and MHRN meetings<br>Promotional materials in 2 sites. | Lit and policy review                               | Develop interview schedule                                   | Engage PCRN and MHRN<br>Apply for research passport and local approvals  |
| <b>2: May</b>         | PMG&AM<br>AG  | PCRN and MHRN meetings<br>Promotional materials in 2 sites. | Lit and policy review                               | Identify sample (12 per site)                                | Work with MHRN and PCRN in set up<br>Review tools and plan pilot   |
| <b>3: June</b>        | PMG<br>Gain R& D approvals                              | Piloting data collection and stakeholder interviews         | Lit and policy review                               | Set up interviews  | Pilot interview with 8-10 individuals with SMI in London and Devon   |
| <b>4: July</b>        | PMG&AM<br><i>RA starts in Plymouth</i><br>First AE held | Piloting data collection and stakeholder interviews         | Lit and policy review                               | Interviews<br>Begin analysis<br>Resource databases developed | Pilot interview with 8-10 individuals with SMI in London and Devon and revise tools                                    |
| <b>5: Aug</b>         | PMG<br>Recruit IRs                                      | Piloting data collection and stakeholder interviews         | Lit and policy review                               | Interviews<br>Analysis<br>Databases<br>Developed             | Continue to revise and pilot tools   |
| <b>6: Sept</b>        | PMG&AM<br>Recruit IRs                                   | Attend conferences and relevant meetings                    | Review report produced                              | Interviews<br>Analysis interviews                            | NRES resubmission minor / major ethical amendment with new tools<br><br>Finalise recruitment strategy with practices   |
| <b>7: Oct</b>         | PMG<br>Submit 1 <sup>st</sup> progress report to        | Meet GP practices to set up recruitment processes           |   | Analysis interviews  | Work with PCT ICT to access QOF SMI registers in practices across case study sites                                     |

|                     |   |   |                                    |   |   |
|---------------------|---|---|------------------------------------|---|---|
|                     | NIHR SDO  |   |                                    |   | Recruit to cohort study in 2 sites by letter from PCT<br><br>Follow-up by phone from GP (practice nurse)                              |
| <b>8: Nov</b>       | PMG&AM  | Researchers attend local forums / meetings  |                                    | Interview report written                                      | Recruitment continues<br>Start interviewing – 10<br>Follow-up via community teams if recruitment unsuccessful via GP                  |
| <b>9: Dec</b>       | PMG<br>Second AE held                               | E-newsletter I                              | Review presented at AE to advisors | Recruitment strategy finalised<br>Finalise survey content     | Recruitment continues<br>Interviews – 20  |
| <b>10: Jan 2012</b> | PMG&AM  |   |                                    | Develop survey  | Recruitment continues<br>Interviews – 20<br>First 5 in depth interviews   |
| <b>11: Feb</b>      | PMG   |   |                                    | Pilot survey  | Recruitment continues<br>Interviews – 20<br>In-depth interviews 5<br>Transcription and coding   |
| <b>12: Mar</b>      | PMG&AM<br>Submit 2 <sup>nd</sup> report to NIHR SDO | Researchers attend local forums / meetings  |                                    | Finalise data bases   | Recruitment continues<br>Interviews – 20<br>In-depth interviews 5<br>Transcription and coding<br>1 <sup>st</sup> analysis workshop IR |
| <b>13: April</b>    | PMG<br>Short-term RA starts                         | E-newsletter II                             | Update Lit and policy review       | Circulate survey to leads in organisations and email contacts | Recruitment continues<br>Interviews – 20<br>In-depth interviews 5<br>Transcription and coding   |
| <b>14: May</b>      | PMG&AM<br>Third AE held                             |   | Update Lit and policy review       | Email survey to contacts                                      | Recruitment continues<br>Interviews – 20<br>In-depth interviews 5<br>Transcription and coding   |
| <b>15: June</b>     | PMG   | Researchers attend local forums / meetings  |                                    | Email reminders sent  | Interviews – 20<br>In-depth interviews 5<br>2 <sup>nd</sup> Analysis workshops with IRs   |
| <b>16: July</b>     | PMG&AM  | Arrange sessions to apply model in Plymouth |                                    | Close survey<br>Analysis                                      | In-depth interviews 5<br>Network analysis<br>Transcription and coding   |
| <b>17: Aug</b>      | PMG   | Arrange sessions to apply model in Plymouth |                                    | Analysis<br>Write up survey                                   | In-depth interviews 5<br>Network analysis<br>Transcription and coding   |
| <b>18: Sept</b>     | PMG&AM<br>Submit 3 <sup>rd</sup> report to NIHR SDO | Researchers attend local forums / meetings  |                                    | Identify second round participant (12 per site)               | Network analysis<br>3 <sup>rd</sup> Analysis workshops with IR  |
| <b>19: Oct</b>      | PMG   | E-newsletter III                            |                                    | Present survey data to LAN<br>Second round interviews         | Network analysis<br>In-depth interview analysis   |
| <b>20: Nov</b>      | PMG&AM  | Sessions held in Plymouth                   |                                    | Second round interviews                                       | Network analysis<br>In-depth interview analysis   |

|                     |                         |  |                                       |  |   |
|---------------------|-------------------------|--|---------------------------------------|--|---|
|                     |                         |  |                                       | Analysis   |   |
| <b>21: Dec</b>      | PMG                     | Sessions held in Plymouth                                  | Update Lit and policy review          | Second round interviews<br>Analysis              | Collating data network analysis and depth interviews<br>Final workshop with IRs |
| <b>22: Jan 2013</b> | PMG&AM<br>Final AE held | Hold feedback events in sites<br>Sessions held in Plymouth | Update Lit and policy review          | Link org and individual data                     | Link org and individual data<br>Feedback to AG                                  |
| <b>23: Feb</b>      | PMG                     | Final E-newsletter IV                                      | Write final report<br>Feedback<br>LAN | Prepare papers for publication and output guides | Prepare papers for publication and output guides                                |
| <b>24: Mar</b>      | PMG&AM                  | Researchers attend local forums / mtgs                     | Write final report                    | Write guide for PCTs                             | Write user guide to community health networks                                   |

**Key:** PMG = project management group – which will combine with analysis meetings bi-monthly (PMG&AM); AE= Advisory event; RO = research officers; IR = involvement researchers

## 7. Ethics

Ethical approval will be sought from NRES for this project prior to the project commencing once grant funding has been confirmed. R&D approval from our two main case study sites (NHS Devon and Hammersmith and Fulham PCT), as well as Plymouth PCT, will also be obtained within the first 3 months of the project. We have carefully considered the ethical issues that may be raised in conducting this research project with a vulnerable group of participants. In this section we outline the main points to be considered.

### 7.1 Informed consent

The issue of obtaining informed consent is particularly important when working with a vulnerable group of participants. Potential participants will be randomly selected from GP SMI registers across the two case study sites. GPs will be asked to de-select individuals whom they believe would be too unwell to take part, or to pass this opt-in process to members of the mental health community team if GPs feel unable to make this assessment. Having established a sampling frame, selected participants will then be sent a letter from their GP practice to ask them if they would like to attend an interview to discuss and participate in the project. The letter will include an information sheet detailing the purpose of the project and exactly what participation involves. They will be asked to return an expression of interest form in a stamped addressed envelope to the research team saying if they would like to attend or not participate. It will be emphasised that returning this form does not in any way represent a commitment to participating in the study. On the day of the interview, the project researcher would again go through the information sheet. Following this, if the participant is still happy to participate, written informed consent will be obtained prior to beginning the interview. We consider this process to be more accessible to people with SMI than being sent a long information sheet and being asked in writing if they want to participate. In case of any distress experienced by participants in the course of the interviews, they will be referred to their GP or care manager for further support should the need arise. The LAN will provide additional guidance on support mechanisms locally that need to be included in the study materials. All



the interviews will take place at a GP surgery or other health facility and thus assistance would be accessible if required.

### **7.2 Confidentiality and data protection**

All data held will be strictly confidential. Each participant will be given a unique identifying number. This will be the only identification on all data sources relating to participants e.g. transcripts and digital audio recordings, interview notes and survey. The lists matching participants to unique identifying numbers will be known only to the project team. These lists will be stored in a locked filing cabinet, apart from all other data on secure premises. Audio recordings will be kept on password protected central servers on the two research sites. Consent forms will also be stored apart from this data in a locked filing cabinet. These measures comply with the 1998 Data Protection Act.

### **7.3 Withdrawal from study**

It will be made clear to participants that participation is voluntary and that they are free to withdraw from the discussion of particular issues or from the entire interview should they feel uncomfortable at any time. Also, participants are free to terminate their involvement with the project at any time, and will be given the option to have any previously recorded data excluded from the study and destroyed. Participants will be given the opportunity to raise questions with the researcher both before and after each interview, should any issues arise. Participants will also be provided with the project researcher's contact details in case of need for clarification of any issues following each interview.

### **7.4 Paying participants**

We have decided that each participant (not professionals) will be paid the nominal sum of £20 to say 'thank you' for participating in the study after each interview. This figure has been set as it is judged to be small enough to not to coerce anyone into taking part, and large enough indicate the gratitude of the project team. Practitioners participating in the study will be offered a certificate of participation in research which they may use for CPD purposes.

## **9. Service users**

Service users with experience of SMI will be actively involved in the delivery of this project through membership of local delivery teams (two in each site). Rethink currently employs a consumer researcher within the team, who has commented upon the proposal. We have invited a GP (who is also a carer) to join our advisory group. The involvement of stakeholders is important to ground the study in issues that are of most relevance to those in receipt of health services. It also ensures that all the study materials – from study information sheets and letters of invitation, through to e-newsletters and knowledge outputs are written in a format that is most accessible to service users and carers, as well as NHS managers and practitioners.

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*This protocol refers to independent research commissioned by the National Institute for Health Research (NIHR). Any views and opinions expressed therein are those of the authors and do not necessarily reflect those of the NHS, the NIHR, the SDO programme or the Department of Health.*