## DETAILED PROJECT DESCRIPTION

#### Full title of project

Location of care for people with serious mental illness: implications for service use and costs

#### Aims and objectives

The overall aims of this project are to compare the characteristics, service use and costs of patients with severe mental illness (SMI) who are managed in primary and secondary mental health care and to evaluate different interventions to facilitate the transition from secondary to primary led care.

The specific objectives are to:

- a) Identify people with SMI whose care is (i) managed in primary care or (ii) managed in secondary care
- b) Identify people with SMI who could be potentially transferred from secondary to primary care management
- c) Compare the demographic and clinical characteristics of these groups
- d) Measure and compare the use of services and calculate service costs for these groups for the year prior to identification and the subsequent 3.5 years, adjusting for clinical and demographic differences in the groups
- e) Generate cost prediction models to enable resource consequences of patients with specific characteristics who are transferred from one form of care to another to be estimated
- f) Produce survival models to identify characteristics associated with time to transition to a different group
- g) Investigate the experiences of patients receiving support from interventions designed to facilitate the transition from secondary to primary care
- h) Assess the economic impact of interventions to facilitate transfer of care management

#### Background

In this study we are focusing on care received by people with SMI. For practical reasons SMI is defined in this project as the same as for inclusion in the SMI register in primary care; a person with a diagnosis of schizophrenia, bipolar disorder or other psychosis i.e. non organic psychosis [1]. The Quality and Outcomes Framework (QOF), which the SMI register is part of, is an element of the general medical services contract in Britain designed to encourage, and incentivise good clinical practice especially in the management of long term conditions such as SMI.

People with SMI may require care from a wide range of health and social services. Secondary mental health services are vital to many and include inpatient and general and specialist community care. Patients receiving secondary care will usually be under the Care Programme Approach. However most people with SMI will be in contact with other services including their GP. For many, primary care is the main focus of care. A recent study suggested that about 25% of patients with SMI are managed entirely in primary care [2]. This study focusses on care provided in Lambeth, and the rate of primary care management is thought to be higher there (personal communication, Lambeth PCT). While many benefit from specialist services it is likely that some of this group are well enough to be managed in primary care given adequate support e.g. in relation to their social and economic situation [3]. Primary care has been shown to be as effective for some patients as secondary care across a wide range of areas [4] but it is likely that this is variable. Providing care in primary care settings has the potential to support a holistic approach to meeting mental, physical and social needs [5]. People with SMI are more likely to have physical comorbidities than the general population, and primary care databases can help to investigate this [6]. There may be a third group of people with SMI who are not being actively managed in either primary or secondary care. This may be appropriate if recovery has occurred but may also be a problem of engagement with services [7]. However, these will still usually be a sub-group of those registered as being managed in primary or secondary care (and we will identify these in the subsequent analyses).

The extent to which patients transfer between secondary and primary care settings is unclear, for instance the criteria used tend to be implicit rather than explicit and may vary between mental health teams and according to the perceived or actual capabilities of the practice a patient is registered with. GPs recognise the need for access to specialist knowledge [8] and successful and sustainable transfer to primary care requires effective links with secondary care services that can be accessed promptly when needed [9]. Interventions exist to provide links between primary and secondary care and to prevent inappropriate referrals [10]. In 2011, Lambeth Primary Care Trust (PCT) in south east London initiated an approach to support patient centred and sustainable transfer from secondary to primary led health and social care for people with SMI. This consists of three specific interventions: a) a Primary

Care Mental Health Support Service (PCMHSS), led by a GP with special interest in mental health, to enable practices to manage the long term treatment, care and recovery of people with SMI and others with complex life problems with a mental health component not otherwise appropriate for a secondary care referral; b) a Community Options Team provided by the voluntary sector to support transition of people moving from secondary mental health services to the care of their GP that focuses on action planning with the client to support recovery and social inclusion and access to mainstream services; and c) Peer Support offered by a local users and carers organisation (Vital Link). This is an informal arrangement for people with mental health problems who wish to have the support of someone with a mental health history to help them regain confidence and to support participation in daily life. These initiatives are complemented by social care support using a personalisation approach including the potential for a personal health budget, and an information and resource service to support access to mainstream services e.g. employment, housing and benefits.

Trials of interventions such as these are an important source of evidence as to their effectiveness and costeffectiveness. However, this evidence takes time to generate and data collected routinely, supplemented with economic modelling, is a pragmatic alternative. Primary and secondary care datasets are well established in Lambeth and have been used to investigate a range of healthcare issues [11]. Recently developed capacity to link these systems provides an excellent opportunity for research at the primary-secondary care interface. Key data sources for this study are the Clinical Record Interactive Search (CRIS) system (an extensive clinical case register of secondary mental health care services provided by the South London and Maudsley NHS Foundation Trust), Lambeth DataNet (a system to extract and aggregate primary care data from Lambeth general practice IT systems) and a commercially purchased package that links primary care data though DataNet with Hospital Episode Statistics for the purposes of data validation and risk stratification. Proceadures are in place for linking these anonymised datasets for the purposes of research activities.

Over and above cost considerations, little is known about how changes in the location of care will affect patients' mental health care experiences. Despite considerable policy interest in the delivery of mental health services via primary care it is generally acknowledged that research evidence in this area is very limited [12]. Studies looking at the views of mental health service users themselves have, in the past, drawn mixed conclusions. While one study concludes that service users view primary care as the 'cornerstone' of their physical and mental health care [13] another earlier study showed that a majority (59%) of patients with a severe mental illness preferred their GP to have only low involvement in their mental health care [14]. Another more general study of users' views found that, for help during a mental health crisis, service users were least likely to favour a service based on GP support alone [15]. Also a Mental Health Foundation study on users' views of stigma and discrimination reported a high percentage (44%) who felt that their GP discriminated against them because they had a mental illness [16]. In recent years there has undoubtedly been much greater emphasis on improving mental health provision in primary care [17]. However, it is not yet clear whether this will also translate into improved services for those with more severe mental health conditions.

#### Need

The NHS is being asked to make unprecedented savings over four years to 2014-15. While arguments exist as to how to define these, care options that maintain quality but at a lower cost than comparators are of particular interest. Mental health problems result in high costs [18]. About 12% of the NHS budget goes on mental health care [19] with the bulk of spending on secondary mental health services. While there are treatments and therapies with established efficacy for people with SMI, there is not a consensus as to the best location of care for patients. This is important because prices and costs differ markedly according to where care is provided due to differences in contractual arrangements, staff availability, infrastructure costs and overheads. Furthermore, similar to acute providers, care from specialist mental health providers will in the future be financed using payment by results and the tariff may be higher than care provided elsewhere. This suggests that for some patients (e.g. those requiring relatively less specialist care than others) transfer from secondary care to primary care may be justified after specific needs have been met by appropriate secondary care services. Other patients may initially come into contact with primary care services and it may again be considered appropriate to maintain their care in this location. Providing more care, where appropriate, in primary care settings may also help to address the high level of physical comorbidity in people with mental health problems [20, 21].

The referral flows across primary and secondary care boundaries are determined by health service configuration factors such as relative ease of access to specialist services and GPs. Perceived strengths of specialist services could

include being a conduit to therapies not available in the practice and being a means for accessing social care services. Some general practices may feel very capable at dealing with SMI patients in distress while others may feel less confident. Practices themselves may differ in their attitude to SMI work. Some may consider it part of their role and take real pride in looking after 'difficult' patients. Others may feel the complexity is too great. Providing data on the cost and benefits of transfers can inform investigations and assessments of the process of referring between these different agencies.

There are risks in transferring the lead role for coordinating and managing mental health care from secondary to primary services. For instance, if there is lack of rapid access to specialist mental health input unplanned or emergency care may be more frequent. There is thus a need to identify at what point patients may need care from which type of service and what the cost and clinical consequences of this are. Determining the likelihood of unplanned care in specialist settings for patients managed in or transferred to primary care is information that is crucial for those planning services as is time to such care contacts. It is further necessary to know what the costs of care would be for patients who are either not transferred or whose transfer is not as rapid as that of others. Information on these issues is currently lacking but may be derived from routinely available data. Application of methods to achieve this will be of benefit to future assessments of patient care.

Specific services have been set up in Lambeth to facilitate transfer of care to primary care and to maintain care in that location. As with any healthcare interventions these must be evaluated in terms of cost-effectiveness. There is a need to conduct evaluations efficiently and we should make best use of existing datasets as an alternative to more expensive and time-consuming trials. These data will allow simulation models which assess the costs and benefits of different interventions to be populated. There is also a need to assess care that is provided at a 'whole-system' level. The use of modelling is needed in such situations to ensure that results are generalisable. Models allow this by enabling specific characteristics/variables to be changed to reflect different circumstances in other areas.

This proposal therefore addresses a number of policy needs. It will also take account of the experiences and views of people with mental health problems who are being transferred from primary to secondary care with focus groups to advise on specific components of the project including a user reference group. The latter will provide a necessary perspective on the analyses and the interpretation of the findings. Therefore, an important, parallel, component of the study will be to investigate users' views and experiences of these transition services. The focus groups will provide a necessary perspective on the analyses and the interpretation of the findings from them.

## Methods

The proposed study consists of three components: 1) a quantitative component based on routinely collected health records, 2) a qualitative component investigating users' views and experiences, and 3) an economic modelling component. Combining different methodological approaches in evaluation research, as we propose, is increasingly advocated for studies that set out to investigate complex health and social care interventions such as these [22]. The intention is that the results of each phase of the study will then inform the next phase so that a more complete picture of the impact of the location of care can be achieved. A detailed flow diagram describing the study is shown on page 13 and a high-level diagram indicating links between the components and their relationship to the study objectives is shown on page 14.

# Component 1: Investigation of characteristics associated with location of care management, comparison of service use and costs, and analysis of time to change of location in care management

People living in Lambeth who have severe mental illness (SMI) will be identified from the SMI registers in primary care. These are compiled as part of the Quality and Outcomes Framework (QOF) with SMI defined as schizophrenia, schizotypal personality, persistent delusional disorder, acute/transient psychotic disorders, induced delusional disorder, schizoaffective disorders, manic episodes, bipolar disorder, and severe depression with psychosis. These diagnoses are based on READ codes entered into GP records. The prevalence of SMI in Lambeth according to the QOF returns for 2010/11 was 1.4% compared to a national average of 0.8%. For each person identified we will seek to produce a dataset containing information on demographic characteristics (age, gender, ethnicity, marital status, first part of postcode), clinical details (length of time since first service contact, HoNOS score where available), concurrent physical health conditions and risk factors, primary care contacts, secondary care contacts (inpatient and community), medication prescribed, social care contacts, and use of secondary non-mental health care services. Sources for these data are described below.

The Clinical Record Interactive Search (CRIS) system is an extensive clinical case register for secondary mental health care services. It allows searches to be made of the fully electronic patient records system of the South London and Maudsley NHS Foundation Trust (SLaM) and extracts data for secondary analysis including free text fields if required. The data resource contains full anonymised clinical records on over 180,000 service users, of whom about one-quarter are Lambeth residents. Data include contacts with services and medication as well as demographic and clinical characteristics such as Health of the Nation Outcome Scale (HoNOS) scores. Correspondence and notes in free-text format are also included. Data are available from 2007. An advantage of CRIS is that it retrieves information that is collected as part of routine clinical practice rather than relying on extra data collection exercises. Data from SLaM's 'electronic patient journey system' (ePJS) are converted into xml format to allow database searches. Key patient identifiers (name, date of birth, address) are removed not only from structured fields but also from text in order to provide an anonymised dataset for research purposes. However, a unique ID number is still required to avoid duplication and this is derived from an algorithm based on NHS numbers. The algorithm is 'hidden' and not available to researchers. Use of CRIS is governed by an oversight committee, chaired by a user of mental health services, which reports to the SLaM executive. A full description of the development and use of CRIS has been published [23]. Data from CRIS have been used in a range of projects including a series exploring the life expectancy of people with SMI, substance misuse and depression [24, 25].

Lambeth DataNet is a primary care database covering all but one Lambeth general practices. It is derived from coded data (including the SMI register) collected by practices and entered on their clinical systems. Extractions can include any routinely coded GP data such as GP consultations, health screening, long term conditions and prescribing. A unique aspect of DataNet is that for nearly 10 years most of the practices have been collecting high quality demographic data on e.g. ethnicity, preferred language/communication needs, religion that enables studies to assess equity of access to and outcomes of primary care. It is possible to link patient records from one year to the next via their anonymised NHS number so that we now have longitudinal data for all patients that have been registered since 2008. DataNet allows analysis of other key demographic and clinical details for patients on the SMI register (such as ethnicity, language, Body Mass Index, smoking status, presence of other long term condition etc). Data are encrypted to ensure anonymity but secure methods of de-encryption by a third party are in place to link with other data sources. This will be essential in this study and the NHS identifier will be a key linking data item.

As stated above there is the capability within DataNet to extracts information on the number of contacts that patients have with primary care staff clinical staff. However, it has been established that a query can be written and these data extracted by DataNet analysts and would be of good quality. This would require time to write, test and validate database queries in the three different primary care IT systems in use in Lambeth practices. About half of the practices in Lambeth should be able to run the queries with no further support required. The remaining half would require further support from analysts either in the form of chasing up queries or providing assistance in actually running them (including site visits). Further data cleansing and processing is then required to ensure data leaving the PCT does not have any identifiable characteristics stored in free text (if any free text fields are required). Required analyst time is included in the costings. Each practice also gives individual permission to extract data for any project using DataNet according to an agreed protocol. (A DataNet Steering Group chaired by the PCT has oversight of what research is done using DataNet.) Time and administrative support to gain consent for all 52 practices is included in the submission.

Hospital Episode Statistics (HES) are a record of all NHS inpatient episodes by patients in England. Data are provided by all NHS providers and include details of length of stay, clinical diagnosis, and demographic information. Data of specific interest here will be those relating to inpatient stays (for physical and mental health problems) in hospitals other than those managed by SLaM. This is a relatively small proportion of Lambeth residents. There now exists a static data link between HES and CRIS.

The PCT also uses a commercially purchased arrangement to link primary and acute hospital services data for the purposes of data validation and risk stratification so as to deploy community matrons to prevent unplanned care in people with long term conditions. It is feasible given the appropriate governance arrangements to make an additional link to combine the mental health services data with the primary and acute services data to study the effects of transfer from secondary to primary care on a cohort of people with SMI. This dataset is to be expanded in 2012/13 to cover community service contacts for those in the borough.

#### Data merging issues

Data contained in CRIS, HES and Lambeth DataNet are encrypted for the purposes of confidentiality. Proceadures have been established to combine these datasets by trusted third party de-encryption/re-encryption. This has already been carried out for previous studies between CRIS and DataNet and between CRIS and HES. We have already been granted data sharing approval by the local Caldicott guardian to link the two datasets. The linkage procedure would be carried out behind the fully secured NHS firewall. DataNet data are already combined with acute sector data using the commercial risk stratification and data validation tool purchased by the PCT. The only remaining linkage is that between CRIS and this database.

While these datasets can be linked we realise that this will still be challenging. We have factored in time at the start of the project to ensure that this is done reliably and to identify any problems that may occur.

#### Definition of groups for comparison

Data will be obtained on service contacts and clinical characteristics for the 12 months prior to the SMI register index date (January 2010). These data will be used to categorise patients as being under secondary care management or primary care management according to whether there is a record of discharge to the GP and or the secondary care record is identified as inactive. If there is any doubt it will be possible to clarify by identifying which clinician is responsible for prescribing any antipsychotic medication.

#### Characteristics of patients managed in different settings

Information from DataNet and CRIS will be retrieved on: age, gender, marital status, number of children, ethnicity, employment, GP practice, diagnosis, and time since first contact with mental health services. As comorbid physical health problems can influence the use and costs of health care services, we will also use DataNet to collate indicators of physical health (e.g. body mass index), including the presence of other long-term conditions e.g. cardio-vascular disease and diabetes. Comparisons will be made between the two groups using t-tests for normally distributed data, Mann-Whitney tests for other continuous data and chi-square tests for categorical data.

#### Service use and cost calculations

Service use data will be obtained for patients on the SMI register on 1 January 2010 and will cover the period 1 January 2009 to 30 June 2013, with the data for the first year specifically used to determine which of the two groups patients will be allocated to. Data will be combined with relevant unit cost data to generate service costs. Unit costs will be obtained from SLaM management accounts, NHS Reference Costs for other hospital-based care and from the University of Kent annual compendium of unit costs for community contacts [26]. Service use will be compared between the two groups (secondary care management, primary care management,) with a focus on the proportion using specific services and the number of contacts. Services included will be emergency acute admissions, psychiatric inpatient stays, contacts with psychiatrists, psychologists, occupational therapists, community mental health nurses, general practitioners and non-mental health specialists. The proportion of patients prescribed psychotropic medication will also be compared including use of Lithium (which is a specific QOF indicator). While all patients included will be categorised either as managed in secondary care or primary care on the index date it is highly likely that many will have had no or little contact in the preceding period. Whether this differs between the two groups will be assessed.

The proportion of patients using specific services will be compared using logistic regression models. The key independent variable will be the group identifier and covariates will include demographic and clinical characteristics that differ between the two groups. Results will be reported with and without this adjustment. The number of service contacts will be compared using linear regression models using bootstrap methods to address the likely skewed distribution of the data. Total costs will be modelled in a similar way but with the inclusion of other demographic and clinical characteristics as independent variables (given that the objective here is to identify cost predictors rather than to adjust for characteristics that differentiate the groups). Separate regression models will be generated for each group and these will be used to 'cross-predict' what the costs would have been for patients with similar characteristics managed in the alternative setting.

#### Identification of variables associated with transition to other locations of care

The location of care for some patients on the SMI register will change over time. We will conduct survival analyses to identify demographic, clinical, and service use variables in the year prior to the index date that are associated with a move from secondary care to primary care or primary care to secondary care. Two separate models will be

produced (one for each form of management) plus a combined model where the original form of care will be entered as a potential predictor variable. Given the multivariate nature of these analyses we will use Cox's regression in these models.

The focus of these analyses is on care provided in Lambeth. This of course raises issues of generalisability. Lambeth has high levels of deprivation and higher than average levels of psychiatric morbidity. However, the advantage in focussing on one area is that we can take a whole systems approach which would be less feasible in a multi-site study. As such we anticipate that the findings of this study will, with necessary qualifications, have relevance for other areas. We will also have access to similar data for Southwark borough and where possible we will make comparisons between the two areas in terms of service use and patient characteristics.

## Component 2: Qualitative analysis of transitional services

This component will explore the experiences and views of service users subject to the transition from secondary to primary care and receiving at least one of the health and social care interventions aimed at supporting people with severe mental illness in a primary care setting. The primary research question for this analysis will be what is the impact on the perceived quality of care of transferring patients from secondary to primary mental health services? Further research questions will be:

- How do patients view the transition process?
- What are service users' views and perceived experience of these primary care mental health services and how do they compare with their views of secondary care services?
- How do perceptions vary among users of different types of primary care service?
- How do their perceptions change over time?
- How do perceptions vary among different types of service user i.e. across different diagnostic, age, gender, ethnic, socio-economic and general practice groups?
- Do patients' views correspond with those of primary care health professionals and if not then how and why do they diverge?

Given the complex nature of the interventions and the fact that these are new, and potentially developing, services an exploratory qualitative approach is proposed. This will comprise a series of semi-structured interviews conducted longitudinally in order to fully explore the transition process. Longitudinal qualitative studies are increasingly being used in evaluation research and are particularly suited to research looking at transition processes [27,28]. Interviews will begin at the point of discharge from secondary care as service users take up the new services. The same respondent will then be interviewed again at a point, up to one year after the transition from secondary care, where they can reflect on their experience of primary care. Interviews will follow a standard topic guide (see outline below) modified according to the type of service received and the interview stage.

An important part of this component will be to achieve triangulation by collecting data from a range of sources, including: health records, the accounts of service users and also the accounts of primary, mental health and social care professionals involved in their care. While the emphasis in this part of the study would be on the accounts of the service users themselves these would be complemented by interviews with workers involved in their care.

A purposive sample of up to 30 service users with a severe mental health problem recently (within the past six months) discharged from secondary care and in receipt of at least one of the three specified primary care interventions will be recruited. Each intervention will be represented by at least ten respondents. Purposive sampling criteria will include service users from a range of socio-economic backgrounds, age, gender, ethnic groups and GP practices and will also reflect a broad range of disease severity. Patients will be recruited via their GP, the PCMHSS, the Community Options Team or Vital Link peer support who will identify and send invitation letters to patients who fit the overall study criteria, targeting specified categories of service user in order to fit the purposive sample criteria.

The study will include a further sample of workers associated with the respondents' care – comprising approximately 3 participants per intervention. For the PCMHSS and Community Options these would be workers assigned to the service users identified and for the peer support intervention provided by Vital Link the relevant peers would be interviewed.

An initial 1.5 hour semi-structured interview will take place at a time point where participants have recently been discharged from secondary care (within the past 3 months) and begun the primary care intervention (i.e. within the first 6 months for the PCMHSS and Peer Support interventions, and the first month for those receiving the Community Options intervention). These will take place at a location chosen by the patient and all interviews will be conducted by an experienced service user researcher. The emphasis in the topic guide will be on service users' previous experience of secondary care, their current circumstances, their views about the transition process, and initial views about primary care services and expectations for the future.

Participants will be interviewed, following much the same process, up to one year later (6 months for the short term Community Options Team intervention). The emphasis in the topic guide will be on their overall views and experience of the primary care service(s) and their reflections on the transition from secondary care. The topic guide will cover the following areas (draft to be developed):

Experience of secondary care

What kind of support was received? What aspect of support was most beneficial? What was most unhelpful? *Experience of transition* How were they informed of, or consulted about, changes in their care and how was this organised? How do they feel about the way this was managed? Experience of primary care What were the initial expectations of the service? What kind of support is being received? What aspect of support is most beneficial / unhelpful? How satisfied are they with the following aspects of care and how does this compare with the previous experience of secondary care? Continuity of care •

- Access to care
- Emphasis on recovery model •
- Stigma / identity as service user •
- Changes in mental health since discharge •
- Crisis management (explore critical incidents) •
- Medication management •
- Referral to specialist care / inpatient referral •
- Physical health care
- Overall experience of mental health care

Also the following aspects of service user's social / economic circumstances will be explored:

- Community integration has the service helped the user to be more integrated in the local community? •
- Social functioning has this changed as a result of using the service? •
- Employment has employment situation changed since discharge? Has transition service helped with • employment?
- Housing / benefits role of service? •

To facilitate this (main) part of the interview a grid would be provided with sections for secondary and primary care to be completed for the initial interviews. Responses for each item would then be added to each section by the respondent and interviewer together. For the follow up interviews a grid showing a time line from the initial interview could be provided documenting service users' experience of primary care services - to be completed by the respondent and interviewer together.

Interviews will be subsequently transcribed and analysed following a structured thematic analysis approach. Analysis will follow the constant comparison method [29,30]. That is, transcripts will be initially coded, by the researcher, using categories derived from the topic guide as a starting point with new codes subsequently added when necessary. Each category will then be compared with the rest, using an iterative process to look for patterns, differences and similarities, to further refine existing categories and create new ones. Data will also be 'criterion referenced' [31] with cases grouped according to a criterion variable representing the outcome of most interest, in this case service users' satisfaction with services, and recurring patterns or themes within subgroups will be identified. Coding and the subsequent conceptual mapping of codes will be carried out using NVivo (version 9) qualitative analysis software. Reflecting the overall study design, analysis will be in two stages, following the initial and follow up interviews, with the results of the first stage analysis then used to inform the topic guide for the follow up interviews. As a final verification stage a second coder will identify themes from a sub-sample of both sets of transcripts to be compared with the first coder's analysis.

#### Component 3: Cost-effectiveness modelling of interventions

Decision models allow the outcomes and costs associated with alternative care process to be investigated via simulations. Model structures simplify the care process such that specific aspects can be focussed on. Advantages of models are that they can be adapted to reflect the outcomes and costs that occur in a variety of settings (and therefore aid generalisability); they allow evidence to be generated in a time and cost efficient way; and they enable interventions to be evaluated that may be precluded using trial methods. We will produce decision models to assess the cost-effectiveness of the Primary Care Mental Health Support Service, Community Options team, and Peer Support. Data generated in Component 1 will serve as a baseline against which the impact on costs of these will be assessed. The first stage in this will be to structure the models followed by 'populating' the models with local data. Finally the models will be tested using sensitivity analyses. The structuring will be key and we will involve service users, clinical staff, commissioners and research staff in focus groups to ensure that the models are acceptable in terms of identifying the key aspects of the care process and for delivering information that is going to be of benefit to those using, providing and commissioning services. We anticipate inviting participants from the qualitative study component (above) to take part in the focus groups which will be facilitated by PM and PS. The structure will map out the pathways through the care system (or relevant aspects of it) following engagement with the intervention. As such, it will need to include the most likely types of service use such as admission, readmission, psychiatrist contact etc. The time horizon for the models will be finalised during the focus groups but is likely to be 1-2 years. Data on the probabilities of different services being used will be largely derived from the databases described above. Changes in these probabilities will be estimated from data collected as part of the record keeping for the interventions themselves. Costs of different events occurring will be calculated again using data already described. The models, once 'populated', will be 'rolled back' to reveal the expected costs of the different interventions.

There will be uncertainty around many of the parameter values used in the model. The impact of such uncertainty will be explored using a series of sensitivity analyses. One-way sensitivity analyses will determine the impact on expected costs of changing specific parameters individually. Threshold analyses will demonstrate to what extent an individual parameter has to be changed by to *qualitatively* alter the overall result. Finally, we will conduct probabilistic sensitivity analyses where a distribution is assumed around each parameter and a large number of random simulations are run based on these distributions. The intent of this is to produce a distribution of costs around the expected value.

The modelling so far described focusses on healthcare costs. It is also important to explore the cost-effectiveness of these interventions and this requires including outcomes data in the models. We are not conducting a clinical trial of these interventions and data do not exist on changes in clinical outcomes. We intend therefore to focus on patient satisfaction and quality of life with alternative pathways of care mapped out by the models and to elicit ratings from those who have used the interventions and who are participating in the qualitative component described above. During the focus groups we will ask participants to complete two measures to rate their expected satisfaction and health-related quality of life following use of the interventions. Satisfaction will be measured with the eight-item Client Satisfaction Questionnaire [32]. The eight items are scored 1 to 4 and a total satisfaction score is produced. The instrument is quick to use and self-administered. The EQ-5D [33] will be used to produce a rating of health-related quality of life. This measures the following domains: mobility, self-care, usual activities, pain/discomfort, anxiety/depression. Each is coded as 1 (no problem), 2 (moderate problems) or 3 (severe problems) and UK-specific utility weights attached [34] to generate quality-adjusted life years (QALYs). It should be stressed that these ratings

are being made by a small sample of patients and they are not the definitive ratings of satisfaction or quality of life for these interventions. However, they will serve as useful initial parameters to use in the models.

## Contribution to collective research effort and research utilisation

This study will demonstrate how patient case registers in specialist mental health care can be linked to primary care and other databases, such as those for acute hospital health services, to measure and analyse the care that is provided to people with SMI. While it is known that such data sources can be linked (and indeed this project builds on earlier work conducted by team members), this has seldom been done in this area (in fact we know of no other research where primary, secondary hospital and mental health data have been linked) and this project will thus be an exemplar to benefit future work. Additional data will need to be requested from general practices through DataNet and this will serve to improve the quality of the different datasets. We plan to publish details of the process of linking these datasets and the potential benefits of doing so.

Establishing patterns of care for people with SMI managed in primary and secondary care settings, and those recently transferred to primary care and the costs associated with this care will provide important information to commissioners and others as to the potential savings that may be made given different approaches to care. It will also serve future research activities where knowledge of 'base-case' costs is required against which costs of innovative services can be compared. We will disseminate information on these patterns and costs of care and also the predictors of these costs. Ascertaining the impact that indicators such as clinical severity (e.g. HoNOS) and demographic characteristics have on costs will help to refine care groupings used for mental health commissioning. The study will also provide important insights into the impact these new transition services will have on service users. Furthermore, adopting an innovative mixed methods study design we will establish a model for integrating qualitative and economic evaluation components into a comprehensive evaluation study.

#### Timetable

Time period	Component 1: Quantitative	Component 2: Qualitative	Component 3: Decision
10/12	Determination of most	Initial recruitment phase pilot	modelling of interventions
11/12	appropriate ways of combining	interviews and refine topic	
12/12	datasets and trial runs	guide	
01/13	Additional data on consultations		
02/13	acquired from local GP		
03/13	practices		
04/13	Collation of baseline data (for	Initial interview phase,	
05/13	year prior to Jan 2010)	transcription and analysis	
06/13	Analysis of baseline data		
07/13			
08/13	Write up of results of baseline		
09/13	data analysis		Focus group held to structure
10/13			models
11/13			Models populated with service
12/13	Collation of follow-up data		use and outcome data and
01/14	(covering Jan 2010-June 2013)	Follow-up interview phase,	analysed
02/14	Analysis of follow-up data	transcription and analysis	Models verified and validated
03/14			using sensitivity analyses
04/14	Write up of results of follow-up data analysis		
05/14			
06/14			
07/14	Final write-up and	Final write-up and	Final write-up and
08/14	dissemination	dissemination	dissemination
09/14			

#### Approval by ethics committees

The study will involve combining linking information from different databases. The research team will only have access to anonymised data. However, governance arrangements are in place for secure linkage and this has recently included using our Caldicott-run data linking service to connect CRIS with Hospital Episode Statistics. Specific ethics cover for this project will be applied for from Oxfordshire REC who are familiar with our work using these databases. The qualitative component of the study will require NHS ethical approval and this will be sought at the beginning of the study.

#### **Project management**

The overall project management will be provided by PM and AP who will meet weekly with the full-time post-doc health economist to be appointed. The project will have a management group consisting of all applicants plus those research staff who are recruited. This group will meet every two months throughout the project. We have invited Professor Jennifer Beecham (University of Kent and London School of Economics & Political Science), an expert in health and social care economics, to chair an independent Project Advisory Group. We anticipate that this group will meet three times during the project.

## Public users/public involvement

A user reference group will be formed and will meet regularly throughout the study. This will be convened by one of the applicants (DR) in partnership with Vital Link, the user and carer organisation in Lambeth that has been extensively involved in designing and setting up the new arrangements, and will be involved in all aspects of the work from setting up the study through to interpretation of results and dissemination. This group will advise as to the formation of focus groups for specific elements of the project (see below). We plan to involve patients in discussions around the models that we will be generating to assess the economic impact of interventions to facilitate transfers from secondary to primary care. This will take place in focus groups with participants recruited who have experience of mental health problems. These groups will also be used to discuss the results from the database analyses and to contribute to reports of these results. We wish to disseminate the results of the study in a way which will be accessible to a variety of groups including patients and to this end we will develop a dissemination strategy in collaboration with patients through the focus groups.

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# High level diagram

