

# Location of care for people with serious mental illness (LOCAPE): implications for service use and costs using a mixed-methods approach

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## Scientific summary

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# Scientific summary

## Background

This study focuses on the health care received by people with serious mental illness (SMI). For practical reasons SMI is defined in this project in the same way as for inclusion in the SMI register in primary care, namely as schizophrenia, bipolar disorder or another psychosis (i.e. non-organic psychosis). The study addresses a number of policy needs. It also takes account of the experiences and views of people with mental health problems regarding their care. The broad aim of the study is to examine the economic implications of different locations of management of care and the views of service users and staff regarding services set up as alternatives to secondary care.

## Objectives

1. To identify people with a SMI whose care is (1) managed in primary care or (2) managed in secondary care.
2. To identify people with a SMI who could be potentially transferred from secondary to primary care management.
3. To compare the demographic and clinical characteristics of these groups.
4. To measure and compare the use of services and to calculate service costs for these groups for the year prior to identification and the subsequent 34 months, adjusting for clinical and demographic differences in the groups.
5. To 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.
6. To produce survival models to identify characteristics associated with time to transition from primary care to secondary care.
7. To investigate the experiences of patients receiving support from interventions designed to facilitate the transition from secondary to primary care.
8. To assess the economic impact of interventions to facilitate transfer of care management.

## Methods

### *Component 1: quantitative analyses*

The analyses were conducted on people in the London Borough of Lambeth registered with general practitioners (GPs) and who had a record of SMI made by their GP. As such, the starting point was to use primary care records, and the source of these was Lambeth DataNet (LDN). This data set was linked to data on secondary mental health care provided in the local area obtained from the Clinical Records Interactive Search (CRIS) database. Finally, we also made a linkage with Hospital Episode Statistics in order to measure the use of inpatient, outpatient and accident and emergency care provided by other hospital trusts.

Patients were defined as being managed in primary or secondary care in two ways. First, we used CRIS to determine whether or not patients had been discharged from episodes of secondary care prior to the index date of 1 January 2011 and not admitted to another episode of care straightaway. Second, we adopted an approach to defining groups based on the services that had been used in the period prior to the index date. If secondary care mental health services had been used in the preceding 6 months, then we assumed that these were patients managed in secondary care. Of the remaining patients, if there had been primary care contacts during the preceding year, then we assumed that they were managed in primary care.

We also defined a 'no care' group, which consisted of patients not in receipt of secondary care services in the previous 6 months or primary care services in the previous 12 months.

Characteristics of patients were obtained from LDN and CRIS and compared between the groups. Service use was measured using the activity data and costs were calculated and again comparisons were made. In order for cost comparisons to be valid we adjusted for background characteristics using generalised linear models with a gamma distribution and log link. Models were conducted with and without Health of the Nation Outcome Scale (HoNOS) scores and prior health-care costs.

To identify patients who were based in secondary care but who could potentially be discharged to primary care, propensity matching methods were used. These resulted in the generation of propensity scores and if these were  $> 0.7$  we deduced that this indicated a strong likelihood of primary care management. Those in secondary care with scores of  $\geq 0.7$  were identified and the differences in their costs in 2010 compared with those of matched participants were computed.

Finally, a series of Cox regression models were produced to identify characteristics that were associated with time to reuse of secondary care. As before, the models were run with and without HoNOS scores (as many patients did not have these).

### Component 2: qualitative analyses

The broad aim of this component of the project was to explore the experiences and views of service users subject to the transition from secondary to primary care and receiving at least one of the local health- and social-care interventions aimed at supporting people with SMI in a primary care setting. These were a community options team (COT), a primary care support service (PASS) and peer support services. The primary research question for this analysis was: what is the impact on the perceived quality of care of transferring patients from secondary to primary mental health services? Further research questions were:

- 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, sex, ethnic, socioeconomic and general practice groups)?
- do patients' views correspond with those of primary care health professionals, and, if not, how and why do they diverge?

Service users who gave their consent were interviewed using a topic guide by a senior researcher of service user interviews. Staff working in the services were also interviewed. Interviews took place at two time points, which were separated by around 6 months. We also held a focus group to discuss service users' experiences of receiving help from their service. Thematic analysis was conducted using an inductive (data-driven rather than theoretical) approach and followed these stages: familiarisation with all the data, generating codes, identifying themes, reviewing themes, defining and naming themes, and finally writing up themes into a report. The senior researcher was assisted by the research interview-trained service user interviewers in identifying, reviewing, and defining and naming the themes.

### Component 3: economic modelling

The aim of this component of the study was to undertake an exploratory analysis to assess the cost of two treatment pathways for mental health service users, that is, triage services and standard care (GP monitoring). A decision model was constructed, which indicated the care pathways followed after being 'triaged' into local community-based services as opposed to usual care led by GPs. Data on probabilities of different pathways being taken were obtained from the local services where possible and costs were derived from local activity and nationally applicable unit costs. A health- and social-care perspective was adopted and the time horizon was 1 year. Sensitivity analyses were carried out on key parameters.

## Results

### *Component 1: quantitative analysis*

Data on a total of 3632 patients recorded by GPs as having a SMI prior to the index date were obtained from 47 GP practices in Lambeth. One practice did not provide data to LDN. The sample size was reduced to 3463 because GP consultation data, which were a crucial element of the analyses, were not available for all practices. A further reduction occurred when using the first definition of comparison groups (i.e. basing this on discharges from secondary care episodes) because 424 patients had not been referred to secondary care. Using this definition we identified 1410 (46%) patients as being under primary care management on the index date and 1629 (54%) patients as being under secondary care management. The second definition resulted in 1311 (38%) patients defined as receiving primary care, 1776 (51%) patients defined as receiving secondary care, and 376 (11%) patients defined as receiving neither form of care.

There were clear differences between the groups. Those in secondary care were more likely to have a diagnosis of schizophrenia than those in primary care, and those in primary care were more likely not to have received a formal diagnosis. There were few differences in demographic characteristics such as age, sex or ethnicity. History of violence, forensic care, physical health problems, use of antipsychotic medication and treatment non-compliance (all according to secondary care staff) were more prevalent among the secondary care group.

Primary care use and costs did not differ substantially between the primary care and secondary care groups. Those not in receipt of primary care in 2010 did use progressively more in subsequent years. Mental health care costs were substantially different, however.

Primary care costs over the follow-up period were associated with being discharged to primary care, but only when previous primary care costs were included in the model along with the HoNOS scores. This indicates that discharge to primary care is associated with a greater change in costs rather than with costs in absolute terms, which seems logical. Higher primary care costs were also associated with the presence of disorders such as asthma and diabetes mellitus and, again, this is not unexpected. When the service use-defined location variable was used it was shown that those managed in primary care had higher primary care costs than those managed in secondary care, but, again, this was only when previous primary care costs were included in the model. Men had lower primary care costs than women and this supports previous work showing that women are more likely to consult GPs than men.

Secondary mental health care costs were consistently associated with a previous history of violence, forensic care, physical health problems and treatment 'non-compliance'. Being discharged to primary care was consistently associated with future mental health care costs, which were about half of those for patients remaining in secondary care. The models for which location was defined according to service use were very similar to those in primary care at the index date and had subsequently lower costs than those in secondary care.

The propensity score models showed that few patients in secondary care had a high probability of being cared for in primary care. As such, the 'excess costs' amounted to only around £150,000 across the sample. The Cox regression models were similar to the models used to predict costs. Key predictors were records of violence, forensic care, physical health problems and treatment non-compliance.

### *Component 2: qualitative analyses*

The PASS and COT service users were very positive about the support that they received, comparing it favourably with support received from GPs and secondary services. In turn, the staff of these services felt positively about their work, but frequent changes in management, turnover of staff, expansion of the teams with concomitant impact on resources, increased caseloads and uncertainties about the future of the service all had a negative impact on morale over time. The service users from one of the peer support services also valued the help that they received and felt that it offered a unique, and egalitarian, source of

support, although this relationship could become strained because the distinction between the roles of helper and helped to some extent remained. The staff of the peer support services felt positive about their role, and felt more appreciated by PASS, COT and GPs and community mental health teams.

### **Component 3: economic modelling**

The average cost of treatment over 1 year for the triage strategy is around 40% of the cost of standard care (£926 vs. £2504). The difference in average cost over 1 year is £1578. Following the sensitivity analyses, the results did not differ much from the base case of a £1578 difference, but there were notable differences. The difference in cost was not sensitive to the cost of support workers or consultants. However, changes in GP and admission cost changed the cost difference by the largest amounts: £81 and £191, respectively.

### **Implications for practice**

This project has analysed the provision of primary and secondary care services for people with SMI. One of the main implications of this work is that there are clear drivers of the costs of care (e.g. history of violence, physical health problems, perception of treatment non-adherence), and even after controlling for background demographic and clinical characteristics the location of care is still crucial. This might imply that there is scope for cost savings as a result of discharging more people into primary care management. However, the propensity score analysis suggests that the characteristics of those in the different settings are similar. An implication of the qualitative analysis and the modelling is that community-based services that can help the transition from secondary to primary care do exist. However, it is evident from this work that the services we investigated often provided care for those not recently in the secondary care system. This implies that better targeting may be warranted.

### **Conclusions**

The quantitative analyses revealed that many people with SMI in Lambeth were not under the care of secondary care services on the index date. This is perhaps unsurprising. Although conditions such as schizophrenia are frequently chronic, for some people with schizophrenia, their episodes of illness may be brief and infrequent. It was also unsurprising that there were substantial cost differences between those cared for in primary care and those cared for in secondary care. However, this difference remained even after controlling for background characteristics, which is of interest. A notable finding is that there were relatively few secondary care patients with a high probability of being cared for in secondary care. This may indicate that for most people the location of care is appropriate.

The qualitative analyses demonstrated the importance of looking beyond resource use. Experiences with COT and PASS were generally positive. Experiences with peer support were more mixed, but this seemed to reflect uncertainty about aims and objectives. Generally it was a valued service.

The modelling showed that the triage strategy is substantially less costly than standard care (continued GP monitoring) over 1 year. This is likely to be the case because triage services (PASS, COT, PASS + COT and peer support) slow the movement to more expensive secondary care services. The sensitivity analyses suggest that this conclusion can be made with some certainty. The results are robust to changes in fundamental modelling assumptions.

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