GENERAL PRACTITIONERS CARING FOR THE LONG TERM MENTALLY ILL: IS SHARED CARE QUALITY CARE?

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Contents List

Contents List........................................................................................................................................... 2

Preface.................................................................................................................................................... 4

Study 1: Outcome of GP Shared care; structured clinical outcome measurement......................... 5

Background ............................................................................................................................................. 5
  Rationale for the study........................................................................................................................... 5
  General practitioners and major mental disorders ............................................................................. 5
  The CLIPP shared care model............................................................................................................. 6

Aims ....................................................................................................................................................... 7
  Overview ............................................................................................................................................. 7
  Research Hypotheses.......................................................................................................................... 8

Methods .............................................................................................................................................. 8
  Instrumentation.................................................................................................................................. 8
  Quasi-experimental design............................................................................................................... 8
  Introduction....................................................................................................................................... 8
  Individual Clinical status measures.................................................................................................. 9
    Diagnostic spectrum and the choice of measures........................................................................... 9
    HoNOS - Health Of The Nation Outcome Scales............................................................................ 9
    RFS - Role Functioning Scale......................................................................................................... 9
    LSP - Life Skills Profile.................................................................................................................... 9
    SF-36............................................................................................................................................... 9
  Carer burden measurement: ............................................................................................................ 9
    Pai and Kapur family burden on and carer interview schedule (FBIS)........................................ 9
  Consumer care perceptions............................................................................................................... 10
    PNCQ – Perceived need for care questionnaire............................................................................. 10
  Recruitment and interviewing.......................................................................................................... 10
  GP shared care recruitment............................................................................................................. 10
  Area mental health service recruitment.......................................................................................... 11
  Interviewing and follow-up ............................................................................................................. 12

Results ............................................................................................................................................... 12
  Population studied............................................................................................................................ 12
  Control (AMHS) group.................................................................................................................... 12
  Experimental (Shared-care) group.................................................................................................... 12
  Quantitative data............................................................................................................................... 13
    Descriptive baseline Statistics and t-tests for Control and Experimental Time 1 Groups; clinical status measures........................................................................................................... 13
    SF-36............................................................................................................................................... 14
    Life Skills Profile (LSP).................................................................................................................. 16
    Role Functioning Scale (RFS)......................................................................................................... 18
    HoNOS Scores................................................................................................................................. 20
  Prospective findings 1: Descriptive Statistics and Repeated Measures ANOVA's for Three Time Points; Experimental Group.............................................................. 23
    Introduction................................................................................................................................. 23
    Table 5: SF-36 table....................................................................................................................... 23
    SF-36 serial data boxplots............................................................................................................. 23
    Table 6: LSP table........................................................................................................................ 25
    LSP serial data boxplots............................................................................................................... 25
    Table 7: RFS table....................................................................................................................... 27
    RFS serial data boxplots............................................................................................................... 27
    Table 8: HoNOS table.................................................................................................................. 29
    HoNOS serial data boxplots........................................................................................................... 29
    Table 9: Longitudinal Clinical outcome measures Summary table........................................... 32
Study 2: Measurement of fidelity of clinical process in GP shared care

Background
Development of management plans for shared care: the transfer summary
Development of management plans in the Area Mental Health Service Setting

Aims
Overview
Research Hypotheses

Methods: Trialing a project evaluation approach to clinical management in the mental health care setting
Applying CIPP TO CLIPP – original proposal
The concept of fidelity in clinical management, and its assessment
Modification in response to reviewers
Operatoinalising the process evaluation methodology
Context Independent Management Plans
Context Independent Activity Summaries
Process evaluation – review of management plans and activity

Conduct of the study
Data collection and collation
Contrasting experiences of data collection
Delay in analysis
Concluding this work, and concluding reporting to GPEP
Priorities for journal publication
Concluding process evaluation with GPEP

References
Preface

This report presents the findings of a research program funded through General Practice Evaluation Program Grant 518 (GPEP 518). The longitudinal evaluation carried out through GPEP 518, set in GP shared care programs in North West Melbourne has involved a range of methodologies with their common focus the evaluation of shared care in one specific model of GP shared care.

The methodologies have included quantitative and qualitative approaches, applied to the measurement of clinical status or carer burden, and also the exploration of a novel methodology for comparison of clinical care delivery across different settings. Because of the complexity of the overall project, the reporting will be divided into two major strands:

- **Study 1**: The first reported study concentrates on outcome of GP shared care as appraised through the application of structured and semi-structured clinical measurement tools. This includes instruments measuring clinical patient status and quantitative and qualitative assessment of carer burden.

- **Study 2**: The second reported study concentrates on the development and application of procedures for measuring the clinical process of care. Included in this description are: the development of a new instrument and procedure for assessing this dimension of service delivery; and the experience derived from its application in this particular setting.
Study 1: Outcome of GP Shared care; structured clinical outcome measurement

Background

Rationale for the study

General practitioners and major mental disorders

Collaboration of general practitioners and mental health services has long been a focus of development in much of the developed world. This has resulted from the finding that patients discharged into the community were lost to follow-up by specialist mental health services (Johnstone, Gold et al. 1984). Therefore, the extent of specialist supervision of the severely mentally ill in the community has increased (Bamrah, Freeman et al. 1991) and also this growth of community psychiatry has led to greater contact between patients with the more severe forms of mental illness and general practitioners. In the past, people with schizophrenia or manic depressive psychosis might have been seen initially by the general practitioner but they would subsequently have spent long periods of time in hospital (Tyrer 1986). The growth of community mental health centres changed this, with the early discharge of patients from hospital leading to increased involvement by general practitioners who become these patients’ first point of contact within the community. Data collected from studies in the UK have shown:

- General practitioners managed up to 25% of patients with schizophrenia, sometimes without assistance from psychiatric services (Harvey 1996).
- Extra workload on their practices resulted, with clients attending surgeries three times more often than the average attender (Nazareth and King 1992).
- Physical problems, probably as a consequence of nutritional neglect and substance abuse, were more common in patients with schizophrenia than the average attender (Brugha, Smith et al. 1989).

In Australia, the Mental Health Workforce Committee (Australian medical workforce advisory committee 1997) has advocated strengthening the role of general practitioners as a means of improving service delivery to patients, providing a management role to people with serious mental illness who need regular medication and monitoring. This is aimed at improving service delivery while freeing resources in mental health for those needing intensive care.

Despite this and other policy commitments to the role of the GP in mental health care, and evidence as above that the role is a clinically significant one, there has been relatively little systematic assessment of the quality of care delivered by GPs to the population of individuals with serious and continuing mental disorders. Where investigation has occurred, the results are not necessarily reassuring. One study showed the drug regimen, prescribed initially by the psychiatrist, was rarely altered by the general practitioner. Further, mental state assessments were carried out more rarely than analogous assessments of patients with chronic physical disorders (King 1992).

Jenkins (1990), writing about the British experience, advocated the use of detailed indicators such as changes in attendance rates, out of hours contacts, mental state,
application of mental health act sections, levels of medication and communications with the mental health team as being needed to establish the significance of planned interventions.

From review of the literature, two trends emerge: the first relates to the necessity of collaboration between general practitioners and specialist mental health services to prevent client loss to follow-up, while the second reflects the recent focus on increasing specialist support of follow-up in primary care.

Primary care liaison psychiatry

In the USA and the UK multiple models of shared care and other collaborative arrangements exist between psychiatric services and general practitioners. Primary care liaison psychiatry particularly has developed in various ways. In “shifted outpatient” care (Mitchell 1985) the psychiatrist sees psychiatric service patients in general practice, while in “shared care” the management of the patient is coordinated using the joint services of general practice and the psychiatric sector. A less common approach is that of “liaison” where difficult cases are discussed with the general practitioner but with no direct involvement (Nazareth and King 1992). The “consultation liaison” model has been suggested as perhaps the most effective in meeting the needs of both GPs and psychiatric services clients (Strathdee and Williams 1984). Guidelines for establishing the model describe a joint venture between where the psychiatrist takes the functioning style of the practice into account and focuses on an evolving collaborative relationship (Mitchell 1983). Two successful strategies include discussion of the referral before and after assessment and allowing prescribing responsibility to remain with the GP. The discussion time inherent to this model increases the GPs understanding of the psychiatric disorder and associated treatments and is cited by GPs as one of the major advantages of this model (Strathdee and McDonald 1992). Through this model, more neurotic and adjustment disorders are seen in psychiatrically based GP services than in psychiatric outpatient clinics. However, a significant number of other chronically psychiatrically ill patients can also be seen in this setting, having the secondary benefit of allowing any physical complaints to be dealt with at the same appointment. This allows greater convenience to the patient with less stigma and consequently better contact is established by the patient with both the primary and psychiatric health care teams (Nazareth and King 1992).

Development of shared care in Australia

In Australia some shared case programs have been the subject of previous systematic reporting (for instance Carr and Donovan 1992). The general practitioners reporting from this project gave favourable impressions of the impact of the liaison attachment service on their referral patterns, their abilities to manage the psychiatric problems of their patients and the quality of the care provided. The evaluation of this project was, however, limited by a short time frame and small project size. The authors highlighted the need for more extensive and longitudinal evaluative research.

The CLIPP shared care model
A specific and large GP shared mental health care initiative has been mounted in Victoria over the last eight years, initially (1995-1996) with a program grant from Mental Health Initiative funding and subsequently with direct funding from the Department of Human Services Victoria. The sustained development of the CLIPP Project (Consultation Liaison in Primary Care Psychiatry) has provided us with an opportunity to evaluate the outcomes from a specifically developed shared care service.

The CLIPP project was developed in the Northwest Area Mental Health Service in collaboration with the Northwest division of general practice. It attempts to synthesise the three models of shifted outpatient care, shared care and consultation liaison. The overall aims relate to two main areas. The first of these is the development of psychiatric liaison attachments to general practices involving collaboration and consultation from sector psychiatrists. This service provides secondary prevention for patients in general practice, as well as developing a collaborative network between mental health services and the general health sector. In line with suggestions for this type of work from the UK and USA, pre-consultation discussion of the patient’s problem is followed by immediate post-consultation discussion of the management plan, providing an educational opportunity for the GP and continuing care for the patient in the community.

The second aspect of the project involves the transfer of a selected group of psychiatric services clients into shared care, with general practitioners using the channels of communication and collaboration developed in the liaison attachments. This model of service delivery provides a supportive mechanism for mental health service clients to be reintegrated into general health care within a seamless service delivery structure. The program processes have been comprehensively reported (see for instance the website http://www.health.vic.gov.au/mentalhealth/publications/clipp/)

This project set out to monitor the progress of clients transferred into shared care arrangements through the CLIPP program with general practitioners of the Northwest Melbourne Division of general practice.

**Aims**

**Overview**

The overall aim of this project was to assess whether care delivered to patients with severe mental illness in the context of shared care arrangements yields acceptable outcomes in terms of measured clinical variables, satisfaction, physical health outcome, financial impact on clients, and carer burden. This central proposition was operationalised within the following set of research hypotheses.
**Research Hypotheses**

1. The transfer of care into the shared care setting will not be associated with a progressive deterioration of clinical status for those patients now receiving care in the primary shared care setting.
2. Care within shared care arrangements will meet with high levels of client and carer satisfaction. These levels of satisfaction will not differ significantly from those of a control group of clients still receiving care from the community mental health service.
3. Clients transferred into shared care will experience measurable and subjectively appreciated progressive improvements in their physical health.
4. The cost implications of the shared care arrangements will be experienced by those clients transferred into them as modest, and not significantly different from a control group of clients still receiving their care from a community mental health service.
5. Carer burden will not be greater than that associated with mental health service care as an option.

**Methods**

**Instrumentation**

**Quasi-experimental design**

The optimal design for his inquiry might be a randomised controlled trial (RCT), however this was not proposed within this program. Such a study would require substantial additional allocation towards funding of the intervention within the research program allocation, in contrast to which this study program has been mounted without making any financial contribution to the service delivery. The health service funded program has to meet performance criteria such as accessibility for referral which would not have been attainable in the context of an RCT, which inevitably introduces additional restrictions to what is then presented as an experimental study condition. This study is naturalistic, and collects information on a group of clients whose care has been transferred to shared care. The initial project proposal did not present a plan for collection of comparison data, rather the approach to Area Mental Health Service (AMHS) consumers was made at the suggestion of reviewers, and provides for contrasts between this group and those in shared care on a number of variables. It is acknowledged that close matching of experimental and control subjects is not possible within this study.

**Introduction**

Through the process of choosing instrumentation we sought to emphasise the breadth of coverage of instruments employed, and to pay a balance of attention to the three domains of: expert defined clinical measures, client-side assessment of consumer satisfaction, and the assessment of effects on carer burden.
Individual Clinical status measures

Diagnostic spectrum and the choice of measures

Of diagnoses in those so far involved in this process of transfer, Schizophrenia constitutes over half; and Mood Disorders a third. Frequent among Mood Disorders would be Bipolar Affective Disorder but controlled severe depressions also feature. Bearing this diagnostic mix in mind, the project team have reviewed the available outcome measures for mental health. The following scales have been chosen for this project, drawing on the results of a recent Commonwealth consultancy (Andrews, Peters et al. 1994).

HoNOS - Health Of The Nation Outcome Scales

The HoNOS (Wing 1994) was developed to monitor whether “the health and social functioning of mentally ill people was being significantly improved.” It is a set of 12 scales completed by a trained mental health practitioner with ratings made on the basis of available information from routine assessments of the patient. Extensive studies show it to have satisfactory reliability and that it is sensitive to change.

RFS - Role Functioning Scale

The RFS (Goodman, Sewell et al. 1993) was developed for measuring the level of mental health functioning. It has four domains (work, independent living and self-care, immediate social network, extended social network) rated on a 4-point scale where each point on the scale has a description attached to it. It has excellent internal consistency, adequate test-retest and inter-rater reliability, adequate construct and criterion-related validity, although sensitivity to change has still to be formally tested.

LSP - Life Skills Profile

The LSP is a questionnaire which can be completed by the clinician or family member (Rosen, Hadzi-Pavlovic et al. 1989). It consists of 39 items assessing general functioning over the previous 3 months and uses 5 scales (self-care, nonturbulence, social contact, communication and responsibility). Test-retest reliability is excellent, inter-rater reliability is adequate, while construct, criterion and content validity are adequate.

SF-36

This questionnaire, derived from the Medical Outcomes Study from the USA, (Ware Sharbourne 1992) has been well researched and validated as a general health measure with some mental health content. It collects measures of disability, mental and physical, and also a self assessment of change in health status compared to a year ago.

Carer burden measurement:

Pai and Kapur family burden on and carer interview schedule (FBIS)
This interview schedule (Pai and Kapur 1981) is semi-structured in nature. The semi-structured approach to data collection enables the presentation of quantitative data but also provides the possibility of qualitative analyses of the descriptions of caregiving burden. The categories of burden defined in the schedule are financial, effect on family routine, leisure, family interaction, and effect on the physical and mental health of other family members. Reliability and construct, criterion and content validity is good.

**Consumer care perceptions**

**PNCQ – Perceived need for care questionnaire**

The Perceived Needs for Care Questionnaire (PNCQ) is fully structured; and has a branching structure which systematically explores perceptions of receiving mental health care, including adequacy of service response. The enquiry proceeds along five branches, probing for consumer perceived need relating to: information, medication, counselling, social interventions and skills training. Reliability and validity are adequate (Meadows, Harvey, et al 2000).

**Recruitment and interviewing**

**GP shared care recruitment**

The recruitment of consumers for inclusion in the study proceeded through different routes dependent on the care setting. For GP shared care patients, the approach was made directly through the CLIPP program nurse. All clients transferred into shared-care arrangements with general practitioners in the North-west area of Melbourne as part of the CLIPP project were reviewed together with the Project-nurse for inclusion into the project. A small number were excluded on grounds of current clinically unstable status. Those not so excluded were approached initially by the clinician, then by the research team. All clients were then contacted by telephone and an appointment made to visit them. At the time of the home visit, the purpose of the project was explained, the plain English statement given to the client and their consent and that of their carer obtained. The initial assessment was then carried out. This included the HoNOS. The SF-36, the RFS, LSP, the PNCQ and the Pai and Kapur Carers Interview Schedule. This route proved effective and most clients approached agreed to participate, resulting in a refusal rate of 15%. This constitutes the response from within the established group of shared care clients. Many of these had been transferred out into GP shared care before the commencement of this study. It became apparent through the study period that if we restricted ourselves to collection of data on transfers under way, then adequate numbers would not be achieved. Also the study would have the weakness of not being an inception cohort study, which was desirable in respect of considering the methodology as a trail of a new treatment. The numbers in this group would be increased if we used clients who had been introduced into the shared care setting earlier. Most of the study instruments were in routine use within the CLIPP program as part of the transfer process assessment. Hence, inception time data was available for most of these patients, although without the close comparability provided by the collection of data by the same raters in the same setting as is available through the sequential research collected data. Nonetheless, the research team considered that the advantage of an inception cohort design outweighed these possible
problems. Hence we decided to include data from these clients where possible, so that the study would more closely resemble an inception cohort study, and so that adequate numbers could be achieved. The data collection, however, through routine service delivery was not 100% completed, since the collection of this material was regarded as a helpful framework for assessment, rather than a universal requirement. Because the collection of the full set of measures was not universally completed within the context of regular service delivery, some of the data sets at baseline are incomplete, and hence total numbers vary between items.

**Area mental health service recruitment**

As described in project progress reports, recruitment of the control group proved more challenging than in the shared care setting. Presentations were given at several community mental health clinics, and letters were sent to every case manager in each of the participating Area Mental Health Services. Despite this effort the response rate was very low. We expressed an interest in recruiting people with higher degrees of stability and lower clinical delivery intensity, and matching on these criteria proved difficult. This difficulty was encountered within the first service contacted - the host service for the GP shared care program. In response to this difficulty the recruitment was extended to other AMHS settings, with somewhat better success.

There appear to be several reasons for this degree of difficulty: the area mental health services have multiple research projects under way and there in some cases a degree of fatigue regarding research was evident on the part of clinicians and possibly clients as well. Although the shared care patients seem to experience an identity with a specific and in some ways special service, and hence are willing to participate in the evaluation of this service, there is no comparative sense of identification within the comparison group. Through the course of the project we extended recruitment to involve five mental health services. In each case we made team presentations and discussed this issue with management, and responded to suggestions initiating changed recruitment strategies, including regular presence of the researcher in the clinic.

It has become apparent that the impact of the shared care program in the areas where it has been implemented is greater than we had anticipated. The shared care program is now caring for some 20% of clients in continuing care within the Northwest area service, a substantial proportion of whom would presumably otherwise have remained in low-intensity case management or regular registrar contact, and so would have been available to provide control data. The available sample of clients suitable for comparison was consequently reduced. Hence particularly within the Northwest area mental health service many potential participants proved to be unsuitable for inclusion in the project as they have much higher frequencies of contact. This proved less the case in other services where shared care had not been so enthusiastically pursued, and some greater success was achieved through contact with mental health services not hosting the specific GP shared care program. However, in all participating services the acquisition of identified names for participation from case managers for the comparison group proved a lengthy and time consuming process and once individuals were approached the refusal rate was over 50%.
Interviewing and follow-up

Generally clients were interviewed at home although a few, from preference, were seen either at GP surgeries or the AMHS clinic. The AMHS group were interviewed once, with collection of necessary consents and the full set of clinical data. The collection of clinical measurement data from these clients was with the purpose of providing for comparative descriptive data for process evaluation and satisfaction data, hence it was not necessary to collect serial clinical data on this group. This clinical profile data was utilised to compare and contrast these clients with those in shared care.

In contrast the shared-care group were approached on three occasions, close to a year apart (+ 1-2 months), extending through a total of two years of follow-up. This involved the research team retaining contact with the clients throughout this time, including through changes in residence, living circumstances and clinical status.

Results

Population studied

Control (AMHS) group

Generally since interviews were conducted on one occasion there were relatively few occasions when the full data were not collected, this occurring due to fatigue through the full interview schedule. Despite the difficulties referred to above, the final number of participants on most measures was 77-78. The exception here was the LSP measure. Here the necessity was to obtain an informant, either carer or case manager who was willing to participate in this rating exercise, and this was not always achieved.

Experimental (Shared-care) group

There were, inevitably, some withdrawals during the long period of follow-up required for this group. The total number recruited for any interviews was 62, out of 81 clients approached (76%), however a number did not complete the full series of instruments. Total numbers in shared care group data were affected by a number of sources of attrition. Firstly, collection of the baseline (inception) data was not universal because of variability in clinical practice. Secondly there was some loss to follow-up through a long period of continued contact. Finally, in a few cases, fatigue through the interview resulted in missing data on some specific scales.

Incomplete series for each specific measure have been discarded in respect of that measure, but preserved elsewhere in analyses if data on another variable is complete, hence totals vary between items.
Quantitative data

Descriptive baseline Statistics and t-tests for Control and Experimental Time 1 Groups; clinical status measures

The presentation of results opens with comparative data on the experimental (GP shared care) and control (Area Mental Health Service) subjects See Tables 1-3. The distribution on many of these sets of ordinal scales was not normal, hence following the tabular presentation of the total scale scores, for each scale there follows a series of boxplots which present the specific item and then subscale distributions for these two groups. The boxplot format is such that the box where displayed covers ± 1SD, the bars ± 2 SD, and outliers are marked where relevant.

The Family Burden Interview Scale is not presented here as this was not a routinely applied clinical instrument only limited inception data is available
SF-36

Table 1: Comparison of SF36 scores between shared care and control groups

<table>
<thead>
<tr>
<th>Scale</th>
<th>Mean (S.D.) for Controls (N=78)</th>
<th>Mean (S.D.) for Experimental (N=47)</th>
<th>Mean difference</th>
<th>t-tests</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental Component</td>
<td>43.4 (12.3)</td>
<td>50.1 (11.26)</td>
<td>-6.8*</td>
<td>t=3.08</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>(p&lt;.05)</td>
</tr>
<tr>
<td>Physical Component</td>
<td>52.8 (12.05)</td>
<td>55.0 (10.53)</td>
<td>-2.2</td>
<td>t=1.03</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>(p&gt;.05)</td>
</tr>
</tbody>
</table>

SF-36 scores boxplots

Histogram

For STUDYGRP= 1

1 'Experimental' 2 'Control'

Histogram

For STUDYGRP= 1

1 'Experimental' 2 'Control'

Histogram

For STUDYGRP= 1

1 'Experimental' 2 'Control'

Histogram

For STUDYGRP= 1

1 'Experimental' 2 'Control'
### Life Skills Profile (LSP)

#### Table 2: LSP table

<table>
<thead>
<tr>
<th>Scale</th>
<th>Mean (S.D.) Controls (N=63)</th>
<th>Mean (S.D.) Experimental (N=54)</th>
<th>Mean difference</th>
<th>t-tests</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-Care</td>
<td>32.8 (5.4)</td>
<td>33.7 (6.2)</td>
<td>-0.96</td>
<td>t=0.90</td>
</tr>
<tr>
<td>Turbulance</td>
<td>42.2 (7.1)</td>
<td>44.1 (5.1)</td>
<td>-1.97</td>
<td>t=1.70</td>
</tr>
<tr>
<td>Social</td>
<td>14.3 (4.0)</td>
<td>15.9 (4.7)</td>
<td>-1.59</td>
<td>t=1.96</td>
</tr>
<tr>
<td>Communication</td>
<td>20.6 (2.7)</td>
<td>21.4 (3.0)</td>
<td>-0.77</td>
<td>t=1.44</td>
</tr>
<tr>
<td>Responsibility</td>
<td>17.7 (2.8)</td>
<td>18.2 (2.0)</td>
<td>-0.53</td>
<td>t=1.14</td>
</tr>
<tr>
<td>Total</td>
<td>126.4 (20.2)</td>
<td>133.4 (18.0)</td>
<td>-6.99</td>
<td>t=1.97</td>
</tr>
</tbody>
</table>

**LSP boxplots**

For STUDYGRP= 1

1 'Experimental' 2 'Control'
Role Functioning Scale (RFS)

Table 3: RFS table

<table>
<thead>
<tr>
<th>Scale</th>
<th>Mean (S.D.) for Controls (N=77)</th>
<th>Mean (S.D.) for Experimental (N=55)</th>
<th>Mean difference</th>
<th>t-tests</th>
</tr>
</thead>
<tbody>
<tr>
<td>Work</td>
<td>4.0 (1.6)</td>
<td>4.8 (1.9)</td>
<td>-0.80*</td>
<td>t=2.55</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>(p&lt;.05)</td>
</tr>
<tr>
<td>Independence</td>
<td>4.6 (1.5)</td>
<td>5.7 (1.8)</td>
<td>-1.05*</td>
<td>t=3.62</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>(p&lt;.05)</td>
</tr>
<tr>
<td>Immediate Social</td>
<td>4.9 (1.3)</td>
<td>5.7 (1.4)</td>
<td>-0.79*</td>
<td>t=3.30</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>(p&lt;.05)</td>
</tr>
<tr>
<td>Extended Social</td>
<td>4.1 (1.5)</td>
<td>4.5 (1.6)</td>
<td>-0.27</td>
<td>t=1.61</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>(p&gt;.05)</td>
</tr>
<tr>
<td>Total</td>
<td>12.6 (4.0)</td>
<td>15.0 (4.9)</td>
<td>-2.33*</td>
<td>t=3.00</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>(p&lt;.05)</td>
</tr>
</tbody>
</table>

RFS boxplots

Histogram

For STUDYGRP= 1

RFS Work

1 'Experimental' 2 'Control'

Histogram

For STUDYGRP= 1

RFS Independence

1 'Experimental' 2 'Control'

Histogram

For STUDYGRP= 1

RFS Social

1 'Experimental' 2 'Control'

Histogram

For STUDYGRP= 1

RFS Extended Social

1 'Experimental' 2 'Control'
Histogram

For STUDYGRP = 1

1 'Experimental' 2 'Control'
HoNOS Scores

Introduction

The HoNOS is a complex instrument with 12 separate scales, which can be aggregated into a total, and then a further set of subscales. The HoNOS Scales contents are as follows:

**HoNOS Scales content:**
1. Overactive, aggressive, disruptive behaviour
2. Non-accidental self-injury
3. Problem drinking or drug taking
4. Cognitive problems
5. Physical illness or disability
6. Problems associated with hallucinations and delusions
7. Problems with depressed mood
8. Other mental and behavioural problems
9. Problems with relationships
10. Problems with living conditions
11. Problems with occupation and activities
12. Overall functional level

Additionally there is the total score and also subscales with content relating to symptoms, behaviour and functional impairment.

**Table 4: Total Score table**

<table>
<thead>
<tr>
<th>Scale</th>
<th>Mean (S.D.) for Controls (N=78)</th>
<th>Mean (S.D.) for Experimental (N=56)</th>
<th>Mean difference</th>
<th>t-tests</th>
</tr>
</thead>
<tbody>
<tr>
<td>HONOS Total Score</td>
<td>10.4 (5.2)</td>
<td>5.1 (3.0)</td>
<td>5.35*</td>
<td>t=-6.88 (p&lt;.05)</td>
</tr>
</tbody>
</table>
Box plots for individual HoNOS scales for experimental and control groups

Histogram
For STUDYGRP= 1

1 'Experimental' 2 'Control'

Histogram
For STUDYGRP= 1

1 'Experimental' 2 'Control'

Histogram
For STUDYGRP= 1

1 'Experimental' 2 'Control'

Histogram
For STUDYGRP= 1

1 'Experimental' 2 'Control'

Histogram
For STUDYGRP= 1

1 'Experimental' 2 'Control'

Histogram
For STUDYGRP= 1

1 'Experimental' 2 'Control'

Histogram
For STUDYGRP= 1

1 'Experimental' 2 'Control'

Histogram
For STUDYGRP= 1

1 'Experimental' 2 'Control'
Prospective findings 1: Descriptive Statistics and Repeated Measures ANOVA's for Three Time Points: Experimental Group

Introduction

In this section are presented tables and, again, box-plots; which describe the sequential course of various clinical measures through at least two years of follow-up.

Table 5: SF-36 table

<table>
<thead>
<tr>
<th>Scale</th>
<th>Mean (S.D.) for Time 1</th>
<th>Mean (S.D.) for Time 2</th>
<th>Mean (S.D.) for Time 3</th>
<th>F-test for overall mean difference</th>
<th>Contrast for Time 1 &amp; Time 2</th>
<th>Contrast for Time 2 &amp; Time 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental Component</td>
<td>50.1 (11.26)</td>
<td>46.6 (12.1)</td>
<td>45.7 (13.4)</td>
<td>F(2,84)=4.6 p&lt;.05*</td>
<td>p&lt;.05*</td>
<td>p&gt;.05</td>
</tr>
<tr>
<td>Physical Component</td>
<td>55.0 (10.53)</td>
<td>55.2 (12.2)</td>
<td>54.0 (13.5)</td>
<td>F(2,84)=1.3 p&gt;.05</td>
<td>p&gt;.05</td>
<td>p&gt;.05</td>
</tr>
</tbody>
</table>

SF-36 serial data boxplots
## Table 6: LSP table

<table>
<thead>
<tr>
<th>Scale</th>
<th>Mean (S.D.) for Time 1</th>
<th>Mean (S.D.) for Time 2</th>
<th>Mean (S.D.) for Time 3</th>
<th>F-test for overall mean difference</th>
<th>Contrast for Time 1 &amp; Time 2</th>
<th>Contrast for Time 2 &amp; Time 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-Care</td>
<td>33.7 (6.2)</td>
<td>32.1 (6.9)</td>
<td>32.5 (6.4)</td>
<td>F(2,90)=3.1</td>
<td>p&lt;.05*</td>
<td>p&gt;.05</td>
</tr>
<tr>
<td>Turbulence</td>
<td>44.1 (5.1)</td>
<td>44.3 (3.6)</td>
<td>43.8 (6.2)</td>
<td>F(2,90)=0.5</td>
<td>p&gt;.05</td>
<td>p&gt;.05</td>
</tr>
<tr>
<td>Social</td>
<td>15.9 (4.7)</td>
<td>13.9 (4.7)</td>
<td>14.2 (25.0)</td>
<td>F(2,90)=7.4</td>
<td>p&gt;.05</td>
<td>p&gt;.05</td>
</tr>
<tr>
<td>Communication</td>
<td>21.4 (3.0)</td>
<td>20.7 (3.2)</td>
<td>20.9 (2.7)</td>
<td>F(2,90)=1.3</td>
<td>p&gt;.05</td>
<td>p&gt;.05</td>
</tr>
<tr>
<td>Responsibility</td>
<td>18.2 (2.0)</td>
<td>18.9 (2.1)</td>
<td>17.9 (3.2)</td>
<td>F(2,90)=2.1</td>
<td>p&gt;.05</td>
<td>p&gt;.05</td>
</tr>
<tr>
<td>Total</td>
<td>133.4 (18.0)</td>
<td>129.8 (16.0)</td>
<td>129.3 (16.8)</td>
<td>F(2,90)=3.1</td>
<td>p&lt;.05*</td>
<td>p&gt;.05</td>
</tr>
</tbody>
</table>

### LSP serial data boxplots

**Histogram**

For STUDYGRP= 1

AssessmentNumber

---

**Histogram**

For STUDYGRP= 1

AssessmentNumber
Histogram
For STUDYGRP= 1

AssessmentNumber

LSP Responsibility

0 1 2 3

Histogram
For STUDYGRP= 1

AssessmentNumber

LSP Total

0 1 2 3
Table 7: RFS table

<table>
<thead>
<tr>
<th>Scale</th>
<th>Mean (S.D.) for Time 1</th>
<th>Mean (S.D.) for Time 2</th>
<th>Mean (S.D.) for Time 3</th>
<th>F-test for overall mean difference</th>
<th>Contrast for Time 1 &amp; Time 2</th>
<th>Contrast for Time 2 &amp; Time 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>RFS Work</td>
<td>4.8 (1.9)</td>
<td>4.4 (1.8)</td>
<td>4.4 (1.3)</td>
<td>F(2,92)=2.83 p&gt;.05</td>
<td>p&gt;.05</td>
<td>p&gt;.05</td>
</tr>
<tr>
<td>Independence</td>
<td>5.7 (1.8)</td>
<td>4.8 (1.7)</td>
<td>4.7 (1.5)</td>
<td>F(2,92)=13.04 p&lt;.001***</td>
<td>p&lt;.001***</td>
<td>p&gt;.05</td>
</tr>
<tr>
<td>Immediate Social</td>
<td>5.7 (1.4)</td>
<td>5.0 (1.4)</td>
<td>5.1 (1.5)</td>
<td>F(2,92)=5.98 p&lt;.005**</td>
<td>p&gt;.05*</td>
<td>p&lt;.05</td>
</tr>
<tr>
<td>Extended Social</td>
<td>4.5 (1.6)</td>
<td>4.5 (1.7)</td>
<td>4.3 (1.4)</td>
<td>F(2,92)=1.21 p&gt;.05</td>
<td>p&gt;.05</td>
<td>p&gt;.05</td>
</tr>
<tr>
<td>Total</td>
<td>15.0 (4.9)</td>
<td>13.7 (4.7)</td>
<td>13.5 (3.8)</td>
<td>F(2,92)=39.34 p&lt;.005**</td>
<td>p&lt;.05*</td>
<td>p&gt;.05</td>
</tr>
</tbody>
</table>

RFS serial data boxplots
Table 8: HoNOS table

<table>
<thead>
<tr>
<th>Scale</th>
<th>Mean (S.D.) for Time 1</th>
<th>Mean (S.D) for Time 2</th>
<th>Mean (S.D) for Time 3</th>
<th>F-test for overall mean difference</th>
<th>Contrast for Time 1 &amp; Time 2</th>
<th>Contrast for Time 2 &amp; Time 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>5.1 (3.0)</td>
<td>8.4 (4.5)</td>
<td>8.1 (4.5)</td>
<td>F(2,96)=21.2</td>
<td>p&lt;.001***</td>
<td>p&gt;.05</td>
</tr>
</tbody>
</table>

HoNOS serial data boxplots

![Histogram for STUDYGRP= 1](image1)

![Histogram for STUDYGRP= 1](image2)

![Histogram for STUDYGRP= 1](image3)

![Histogram for STUDYGRP= 1](image4)
Table 9: Longitudinal Clinical outcome measures Summary table

The following table summarises some of the key findings in respect to the LSP subscales, RFS, HoNOS and SF-36

<table>
<thead>
<tr>
<th>Scale</th>
<th>Mean (S.D.) at Inception into CLIPP care</th>
<th>Mean (S.D) At Inception +1 Year</th>
<th>Mean (S.D) At Inception +2 Years</th>
<th>F-test for overall mean difference</th>
<th>Contrast Inception: +1 Year, significance and effect size#</th>
<th>Contrast for +1 year and +2 Years</th>
</tr>
</thead>
<tbody>
<tr>
<td>LSP</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-Care</td>
<td>33.7 (6.2)</td>
<td>32.1 (6.9)</td>
<td>32.5 (6.4)</td>
<td>F(2,90)=3.2</td>
<td>p&lt;.05 (⇓)</td>
<td>p&gt;.05 (NS)</td>
</tr>
<tr>
<td>LSP</td>
<td>44.1 (4.7)</td>
<td>44.3 (4.7)</td>
<td>43.8 (6.2)</td>
<td>F(2,90)=0.6</td>
<td>p&gt;.05 (NS)</td>
<td>p&gt;.05 (NS)</td>
</tr>
<tr>
<td>Non-turbulence</td>
<td>15.9 (4.7)</td>
<td>13.9 (4.7)</td>
<td>14.2 (25.0)</td>
<td>F(2,90)=7.4</td>
<td>p&gt;.005** (⇑⇑)</td>
<td>p&gt;.05 (NS)</td>
</tr>
<tr>
<td>Social</td>
<td>21.4 (3.0)</td>
<td>20.7 (3.2)</td>
<td>20.9 (2.7)</td>
<td>F(2,90)=1.32</td>
<td>p&gt;.05 (NS)</td>
<td>p&gt;.05 (NS)</td>
</tr>
<tr>
<td>Communication</td>
<td>18.2 (2.0)</td>
<td>18.9 (2.1)</td>
<td>17.9 (3.2)</td>
<td>F(2,90)=2.1</td>
<td>p&gt;.05 (NS)</td>
<td>p&gt;.05 (NS)</td>
</tr>
<tr>
<td>LSP</td>
<td>133.4 (18.0)</td>
<td>129.8 (16.0)</td>
<td>129.3 (16.8)</td>
<td>F(2,90)=3.1</td>
<td>p&lt;.05* (⇓)</td>
<td>p&gt;.05 (NS)</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td></td>
<td></td>
<td>F(2,90)=39.3</td>
<td>p&lt;.05* (⇓)</td>
<td>p&gt;.05 (NS)</td>
</tr>
<tr>
<td>RFS</td>
<td>15.0 (4.9)</td>
<td>13.7 (4.7)</td>
<td>13.5 (3.8)</td>
<td>p&gt;.05</td>
<td>p&gt;.05 (NS)</td>
<td>p&gt;.05 (NS)</td>
</tr>
<tr>
<td>HoNOS</td>
<td>5.1 (3.0)</td>
<td>8.4 (4.5)</td>
<td>8.1 (4.5)</td>
<td>F(2,90)=21.2</td>
<td>p&lt;.001*** (⇓⇓)</td>
<td>p&gt;.05 (NS)</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td></td>
<td></td>
<td>F(2,90)=21.2</td>
<td>p&lt;.001*** (⇓⇓)</td>
<td>p&gt;.05 (NS)</td>
</tr>
<tr>
<td>SF-36 Mental</td>
<td>50.1 (11.26)</td>
<td>46.6 (12.1)</td>
<td>45.7 (13.4)</td>
<td>F(2,90)=4.6</td>
<td>p&lt;.05* (⇓)</td>
<td>p&gt;.05 (NS)</td>
</tr>
<tr>
<td>SF-36 Physical</td>
<td>55.0 (10.53)</td>
<td>55.2 (12.2)</td>
<td>54.0 (13.5)</td>
<td>F(2,90)=1.3</td>
<td>p&gt;.05 (NS)</td>
<td>p&gt;.05 (NS)</td>
</tr>
</tbody>
</table>

#Effect size symbols, where significant p<0.05: (-) <0.15; (⇓ or ⇧) 0.15-0.3; (⇓⇓ or ⇧⇑) >0.3 (NS) Not significant
Table 10: FBIS Family Burden table

As this data was not routinely collected within clinical practice, the presented material relates to the time course of clients within this model of care through year 1 and 2 after transfer.

**FBIS scales are:**
- A. Financial burden,
- B. Effect on family routine,
- C. Burden against leisure activities
- D. Family interaction, negative effect
- E. Physical health of other family members.
- F. Mental health of other family members.

<table>
<thead>
<tr>
<th>Scale</th>
<th>Mean (S.D.) for CLIPP at Time 2 (N=35)</th>
<th>Mean (S.D.) for Experimental CLIPP at Time 3 (N=35)</th>
<th>Mean difference</th>
<th>Repeated measures t-tests</th>
</tr>
</thead>
<tbody>
<tr>
<td>Financial burden</td>
<td>3.3 (3.3)</td>
<td>1.8 (1.6)</td>
<td>1.5**</td>
<td>t=3.2 (p=.003)</td>
</tr>
<tr>
<td>Disruption of family routine</td>
<td>3.5 (2.8)</td>
<td>3.1 (2.6)</td>
<td>0.5</td>
<td>t=1.0 (p=.341)</td>
</tr>
<tr>
<td>Disruption of family leisure activities</td>
<td>2.1 (2.4)</td>
<td>1.7 (1.9)</td>
<td>0.4</td>
<td>t=1.0 (p=.353)</td>
</tr>
<tr>
<td>Disruption of family interaction</td>
<td>3.1 (2.6)</td>
<td>2.5 (3.0)</td>
<td>0.6</td>
<td>t=1.2 (p=.230)</td>
</tr>
<tr>
<td>Effect on physical health of family members</td>
<td>0.9 (1.1)</td>
<td>0.7 (1.2)</td>
<td>0.2</td>
<td>t=0.7 (p=.515)</td>
</tr>
<tr>
<td>Effect on mental health of family members</td>
<td>1.3 (1.3)</td>
<td>1.3 (1.3)</td>
<td>0.0</td>
<td>t=0.1 (p=.916)</td>
</tr>
<tr>
<td>Total Burden</td>
<td>14.4 (9.5)</td>
<td>11.1 (8.6)</td>
<td>3.3*</td>
<td>t=2.3 (p=.026)</td>
</tr>
</tbody>
</table>

** p<.005  * p<.05

- Overall, there is a significant decrease through time in family burden. The most substantial and the only significant change is in the area of financial burden.
FBIS serial data boxplots

Histogram
For STUDYGRP= 1
AssessmentNumber

Histogram
For STUDYGRP= 1
AssessmentNumber

Histogram
For STUDYGRP= 1
AssessmentNumber

Histogram
For STUDYGRP= 1
AssessmentNumber

Histogram
For STUDYGRP= 1
AssessmentNumber

Histogram
For STUDYGRP= 1
AssessmentNumber

Histogram
For STUDYGRP= 1
AssessmentNumber

Histogram
For STUDYGRP= 1
AssessmentNumber

Histogram
For STUDYGRP= 1
AssessmentNumber

Histogram
For STUDYGRP= 1
AssessmentNumber
**Prospective findings 2: Perceived need findings**

Table 11: Proportion of perceived need

<table>
<thead>
<tr>
<th></th>
<th>Information</th>
<th>Medication</th>
<th>Counselling</th>
<th>Social Intervention</th>
<th>Skills Training</th>
</tr>
</thead>
<tbody>
<tr>
<td>Control Group</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Area MH)</td>
<td>81.1%</td>
<td>95.9%</td>
<td>86.1%</td>
<td>59.5%</td>
<td>43.2%</td>
</tr>
<tr>
<td>Experimental</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time 2 (CLIPP)</td>
<td>44.2%</td>
<td>86.6%</td>
<td>65.4%</td>
<td>36.5%</td>
<td>15.7%</td>
</tr>
<tr>
<td>Experimental</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time 3 (CLIPP)</td>
<td>20.8%</td>
<td>93.8%</td>
<td>54.2%</td>
<td>10.4%</td>
<td>12.8%</td>
</tr>
</tbody>
</table>

- The CLIPP consumers have a lower proportion of perceived need than the Area MH group for all categories.
- For the CLIPP group, there appears to be a substantial decrease in perceived need over time for all categories, except for Medication where perceived need increases.
Table 12: Likelihood of Fully Met Need: Odds and confidence intervals

<table>
<thead>
<tr>
<th></th>
<th>Information</th>
<th>Medication</th>
<th>Counselling</th>
<th>Social Intervention</th>
<th>Skills Training</th>
</tr>
</thead>
<tbody>
<tr>
<td>Control Group (Area MH)</td>
<td>3.0</td>
<td>4.5</td>
<td>5.2</td>
<td>0.4</td>
<td>2.6</td>
</tr>
<tr>
<td></td>
<td>(1.7-5.4)</td>
<td>(2.4-8.1)</td>
<td>(2.6-10.2)</td>
<td>(0.2-0.7)</td>
<td>(1.2-5.5)</td>
</tr>
<tr>
<td>Experimental Time 2 (CLIPP)</td>
<td>4.8</td>
<td>10.3</td>
<td>4.7</td>
<td>0.1</td>
<td>1.7</td>
</tr>
<tr>
<td></td>
<td>(1.6-14.0)</td>
<td>(3.7-28.6)</td>
<td>(1.9-11.3)</td>
<td>(0.0-0.5)</td>
<td>(0.4-7.0)</td>
</tr>
<tr>
<td>Experimental Time 3 (CLIPP)</td>
<td>0.7</td>
<td>14</td>
<td>5.5</td>
<td>*</td>
<td>0.2</td>
</tr>
<tr>
<td></td>
<td>(0.2-2.4)</td>
<td>(4.3-45.2)</td>
<td>(1.9-16.0)</td>
<td></td>
<td>(0.0-1.3)</td>
</tr>
</tbody>
</table>

Note: Shaded areas indicate significant odds; * indicates 0 fully met need

- Overall the odds are that if perceived need exists for Information, Medication, and Counselling, it is substantially more likely to be fully met, rather than partially met or unmet. The exception of this is Information need at Time 3.
- For Social Intervention need is not likely to be fully met for all groups.
- The Area MH group is the only group with significant odds of Skills Training need being met.
Table 13: Comparison between the three groups on likelihood of Fully Met Need: Odds ratios and confidence intervals

<table>
<thead>
<tr>
<th></th>
<th>Information</th>
<th>Medication</th>
<th>Counselling</th>
<th>Social Intervention</th>
<th>Skills Training</th>
</tr>
</thead>
<tbody>
<tr>
<td>Likelihood of fully met need at Time 3 compared to Time 2 (CLIPP group)</td>
<td>0.1 (0.0-0.7)</td>
<td>1.4 (0.3-6.5)</td>
<td>1.2 (0.3-4.7)</td>
<td>*</td>
<td>0.3 (0.0-2.8)</td>
</tr>
<tr>
<td>Likelihood of fully met need for CLIPP group at Time 2 compared to Control group</td>
<td>1.6 (0.4-5.4)</td>
<td>2.3 (0.7-5.6)</td>
<td>0.9 (0.3-2.7)</td>
<td>0.3 (0.1-1.6)</td>
<td>0.7 (0.1-3.3)</td>
</tr>
<tr>
<td>Likelihood of fully met need for CLIPP group at Time 3 compared to Control group</td>
<td>0.2 (0.1-0.9)</td>
<td>3.1 (0.8-11.7)</td>
<td>1.1 (0.3-3.7)</td>
<td>*</td>
<td>0.2 (0.0-1.3)</td>
</tr>
</tbody>
</table>

Note: Shaded areas indicate significant odds ratios; * indicates 0 fully met need.

Meeting of perceived need
Overall the odds are that if perceived need exists for Information, Medication, and Counselling, it is substantially more likely to be fully met, rather than partially met or unmet. The exception of this is Information need at CLIPP Time 3, where as set out in table 13, the rate of this perceived need is very low.

For Social Intervention need is not likely to be fully met for all groups. This is pronounced in the late CLIPP data, however again against a low rate for this item. CLIPP consumers have over double the odds of having met perceived need for medication (comparisons with year 1 and year 2, Odds ratios 2.3 (95% CI 0.7-5.6 NS), and 3.1 (95% CI 0.8-11.7 NS), so although these results are not formally significant it is reasonable to say that within this data set, these consumers appear more content with this aspect of their management.

There is no appreciable difference in the consumer evaluation of counseling interventions in either setting evident from these findings (Odds ratios 0.9 (95% CI 0.3-2.7 NS), and 1.1 (95% CI 0.3-3.7 NS).

There are no significant changes in the likelihood of having fully met need for the CLIPP people between Time 2 and Time 3 in all categories, except Information. There is a significant decrease in likelihood of Information need being fully met at T3 compared to T2.
There are no significant differences in likelihood of fully met need between the CLIPP and Area MH groups, except for Information. The Area MH group has a significantly higher likelihood of Information need being fully met compared to the CLIPP group at Time 3 (but not at Time 2).

**Graphic presentation of perceived need findings**

[Graphs showing perceived need findings for Information, Medication, Social Intervention, and Skills Training]
Qualitative data from the Pai and Kapur

The Pai and Kapur Carer Burden interview data will be presented in relation to six domains of Objective Burden (financial, disruption of routine family activities, disruption of family leisure, disruption of family interaction, and effect on physical and mental health) as well as the Subjective Burden experienced by the carer and family. There were no significant differences in the recurrent issues emerging from the qualitative analysis of both the experimental and control groups. At first interview carers expressed the burden experienced at the time of diagnosis and the impact that this had on family life. At the second interview issues emerged that reflected the chronic ongoing experience of living and caring for a family member or partner with serious mental illness.

Financial burden:

Loss of the client’s income was a financial stress frequently expressed by carers. This was coupled with a fear of the future, and anxiety related to the crisis of a family member being given a psychiatric diagnosis. This proved to be the most recurrent theme. Most clients were not able to return to work and cope with the demands of their previous regular employment. This developed into increasing pressures placed on the carer’s career. These included increased responsibilities at home as well as being constantly vigilant because of the uncertainty of the client’s condition. This affected the carer’s ability to focus on work, as they would have liked to do, resulting in a decreased capacity in the workplace and financial loss. Apart from the financial losses related to reduced income, carers reported that they had to fund the often-expensive habits of clients, such as smoking, the irresponsible use of bankcards and gambling. Poor budgeting and attempts to help the client with alternative expensive therapies compounded this. Many carers provided private psychiatric care, including medication costs for their family members. In contrast a few carers reported that clients were managing well, either in their previous employment, part-time work or on their pension. They were not making demands on family expenses and in some instances, were providing much valued childcare and home help.
Disruption of Routine Family Activities:

Where clients were socially inactive preferring to sit watching television most of the time, this created tension in the family due to their lack of involvement in household activities and chores. Where clients were involved in family activities and household duties, this was erratic and infrequent. Carers felt that this added to their burden of caring. The client was at home for the most part and created extra chores in the family without doing anything to help. The preferred isolated and withdrawn lifestyle of most clients interfered with the family's social activities, and friends and extended family withdrew socially from the family over time. Financial stress coupled with the disruptive or withdrawn behavior of the client in the home affected the number of planned family activities. Important social events such as birthdays or anniversaries were often not acknowledged because of this. A common theme was the disruptive behavior of the client, which interfered with the carers’ social plans or the fact that the client did not like being left alone and wanted the carer to stay at home with them. A small number of clients became carers themselves, looking after children, cooking and cleaning. They found a new vocation and were highly valued members of the family.

Disruption of Family Leisure:

The social life of the carers and families spoken to revolved around the client. A small number of clients were able and motivated to socialise, go away for holidays and were happy to be on their own when carers went out. Leisure activities were not affected in these families. However where clients were disruptive at family events, not able or motivated to go away on holiday, socially withdrawn and where the carer was too fearful of leaving them on their own, the leisure time of the family was severely affected over many years. This meant that carers were not able to benefit from respite and this increased the burden of caring. The unpredictable nature of the client’s condition meant that leisure arrangements were erratic and often had to be cancelled. Most clients preferred to spend their leisure time with close family members and not friends or extended family and this resulted in a restricted friendship circle for carers and their families. Most clients did not have insight into the leisure needs of carers or family members. It was difficult for the carer to have a social life outside of this close family circle. Holidays were difficult to plan and organise, and often had to be...
cancelled at the last minute. Carers commented on the frustration of the unpredictable strain of social isolation, lack of respite, inability to have a social life outside of the family and the unpredictable nature of family events.

Disruption of Family Interaction:

Most clients did not seek contact outside of their immediate family, and this impacted on the quality of extended family relationships. Clients’ daily lives were totally absorbed in close family relationships and activities. This created tensions within friendship and extended family circles and resulted in a withdrawal of long standing carer friendships. Some clients were so secluded that they distanced themselves from their siblings and showed little real interest in family issues. The unpredictability of client behaviors meant that family members had to react cautiously. This affected the spontaneity of family relationships. The unpredictable behaviours of clients when they were unwell impacted on the quality of family relationships and family life “changed and was never the same again”. Families became increasingly isolated when relatives and neighbors didn’t visit so frequently and this was a major frustration for


Carers and family.

Effect on Physical and Mental Health:

Themes that emerged about physical health problems reflected chronic problems with back ache, other bodily pains, hypertension, weight gain and headache. Carers reported that the demands placed on them by the client left them with little motivation or time to do exercise, attend to diet and follow a healthy lifestyle. Most of the time they felt exhausted and worried about the future and what would happen to the client. In particular their thoughts were dominated by a fear of the client attempting suicide. These reactions had become a part of their lifestyle and one which they accepted, although it was extremely frustrating. In some cases they impacted on their emotional well being to such an extent, that they had to seek help from a mental health practitioner. More common were problems with sleeplessness, addiction to smoking, constantly feeling tired and a lack of energy to focus on their own health and emotional well being.
Other family members experiencing problems with psychological health

Other adverse effect on health

Other family members sought psychological help because of client's illness/behaviour

Other family members suffering ill health

Subjective Burden:

Most carers stated that they experienced a continuous burden of care which they accepted as part of their commitment to their family member or partner. This impacted on all aspects of their life as well as their physical and mental health. The experience of subjective burden was related to the extent to which clients were socially withdrawn, displaying erratic behaviours and where the outcome was fearful and unpredictable. In a few instances clients were able to continue with their previous life style and this lessened the burden experienced by carers.
Discussion

Clinical status measures

The comparisons between CLIPP transferred clients and the ‘control’ group confirm that the CLIPP consumers are generally of lower severity than those in continuing care within the AMHS setting. This is as expected from the selection procedures for the CLIPP program which prioritise for transfer those who in the long-term may have significant vulnerabilities, but are currently more stable than those requiring longer term multidisciplinary input.

Here we concentrate on the issue of stability of measures of clinical status following transfer into shared care arrangements. The question addressed is whether the transferred care clients maintained acceptable levels of clinical stability within this management setting.

Longitudinal trends

For longitudinal clinical measures, there is an issue of possible difference arising from different levels of familiarity with the client of different raters (Trauer, Duckmanton et al. 1995), however some points can still be made. The scores at time of transfer on all the measures are high in relative terms compared to series reported elsewhere of people with comparable types of mental health problems and who are in area mental health service care (Preston 2000, Trauer, Duckmanton et al. 1997).

Within the LSP sub-scales there is a certain degree of change, some upwards, some downwards through time – and some of these changes reach statistical significance in both of these directions. The magnitude of these changes and also those within the other summary scales are not very large when the operation of the scales is considered. There is then a finding of modest downward trends in some of these variables between inception (transfer) into the CLIPP setting, and repeat measurement after 1 year. However this change does not continue and clinical status measures between one year and two years into the CLIPP model of care show no changes.

There are some negative changes on some sub-scales between time of transfer and year one. However these still leave the consumers’ ratings in a range suggesting high function in comparison to typical studied consumers whose care setting is within Area Mental Health Services. The mean score on total LSP of above 129 places this group well clear of the threshold of around 116 which has been found to be predictive of long-term community tenure. The size of the changes in total LSP score is well below the threshold of 18 points that has been suggested as a level indicative of clinically significant change (Trauer, Duckmanton et al. 1997). For long-term stable tenure in a community setting, within the LSP sub-scales the most important may be non-turbulence (Preston 2000). This variable is essentially stable through the study period. The negative shift between inception into the program and year one in the LSP social subscale may relate to some reduction in the opportunity for social interaction afforded through contacts within the Area Mental Health Service. The experience of intensive support during the transfer process would give us the clinical suspicion that this may distort the clinical variables upwards at the time of transfer. Also, often the
timing of the transfer is selected so as to avoid periods of stressors or other factors that may worsen clinical state, which inevitably introduces a selection bias.

**Burden of care**

Quantitative scores on the Pai and Kapur burden scale lessened over time. At first interview carers gave an account of the history of their caring for the client from the time of diagnosis, and emphasised the heavy objective and subjective burden that they had experienced. At second interview they reported on the burden that they were living with over a long period of time. They had adjusted to the experience of caring and had integrated this into their life style.

**Perceived need findings**

**Proportion of consumers reporting specific perceived needs**

The consumers in CLIPP management have a lower proportion of perceived need than the AMHS group for all categories. For the CLIPP group, there appears to be a substantial decrease in perceived need over time for all categories, except for Medication where perceived need increases.

**Shared care in the broader context of General practice**

The perceived need findings should be considered in relation to the ratings reported by mental health consumers generally of GP care. In Australia generally the GP is rated poorly as a provider of broad counselling interventions (Meadows, Liaw et al. 2001). In contrast, within CLIPP, consumers rate their GPs very highly as providers of this aspect of their care. Medication and information needs are also well met. Some needs which are less well met (Skills training, Social interventions) are those wherein General Practice in Australia generally performs poorly (Meadows, Liaw et al. 2001) and in this study there is only a very small subgroup with these perceived needs. However, detailed examination of responses suggests this finding is related to a small number of consumers who experience some social isolation in the setting of management within the CLIPP program, and this should nonetheless be a focus for attention.

**Summary of findings in respect of clinical measures**

It is reassuring that this study effectively excludes the possibility that there is a long-term progressive decline in clinical status associated with continuing management within this model, and also reassuring that carer burden appears to be declining with time. These results effectively exclude the possibility that there is a continuing loss of function and of symptomatic status occurring in long-term GP shared care within this model.

These results have also given us feedback which has helped us to keep refining the program. This has included exploring ways to better select clients who will do well in the program, and also to develop augmentations to the model that may enhance the experience of receiving care through this shared care model.
Research Hypotheses

For the purpose of concluding our discussion of this aspect of the study program, and may usefully review the research hypotheses as set out in the introduction to this study.

1. The transfer of care into the shared care setting would not be associated with a progressive deterioration of clinical status for those patients now receiving care in the primary shared care setting.
   - This has generally been supported. There may be some loss of clinical status on some indicators between inception and one year, although this might also be explained by inter-rater differences or selection-bias against transfer taking place at times of greater clinical disturbance. However, the results lend support to the proposition that there is not a progressive decline in overall clinical status of clients in care through the program.

2. Care within shared care arrangements will meet with high levels of client and carer satisfaction. These levels of satisfaction will not differ significantly from those of a control group of clients still receiving care from the community mental health service.
   - Generally the meeting of perceived need confirms this, although room for improvement is to be found against consumer expectations on the areas of skills training particularly.

3. Clients transferred into shared care will experience measurable and subjectively appreciated progressive improvements in their physical health.
   - This is not substantially supported; although the general picture is one of stability on physical health measures.

4. The cost implications of the shared care arrangements would be experienced by those clients transferred into them as modest, and not significantly different from a control group of clients still receiving their care from a community mental health service.
   - Data on financial burden suggests that this is not a major problem for care in this setting.

5. Carer burden would not be greater than that associated with mental health service care as an option. This is reflected in both the quantitative and qualitative analysis of the burden data.

Program response to the findings of GPEP 518

The issue of social isolation emerged within these findings, and although carer burden does not seem to be increasing, in absolute terms there is still substantial burden. We have made both of these findings points of focus within the program, and since these data were collected, we have made some targeted improvements.

1. The tracking procedures for assuring specialist review are more rigorous than they were at the time these data were collected. It is hoped that this insurance of more regular consultant contact may provide for some response to the gap in provision of information opening up later in the course of shared care.

2. We have introduced regular multidisciplinary case conferences, generally to allow for a full revision of each consumer’s management at least every three years, and with
attention paid to issues of social isolation and carer burden. These conferences are more comprehensive than the annual specialist review, and have the aim of considering the emerging problems associated with skills training and occupation identified through the program. Additionally use is made of AMHS OT consultancy services also to support those in the program with specific identified needs in this area. There is still room for further improvement in respect of enhancing the range of multidisciplinary contributions available in this coordinated shared care setting and this should be a focus of attention for other shared care models.
Study 2: Measurement of fidelity of clinical process in GP shared care

**Background**

**Development of management plans for shared care: the transfer summary:**

There is a well defined protocol within the CLIPP program for the extraction of information from the mental health services case notes and for the incorporation of this information into a succinct summary of the clients past history for the general practitioner. This is also elaborated, in discussion with the client, General Practitioner and case manager, into a specific management plan. This includes statements of the necessary and suggested activities for the general practitioner at each regular appointment, indicators of cardinal signs of relapse and contingencies to be carried out in the event of such signs. These may involve contact numbers for professionals within mental health services who may be called upon in the event of problems.

A Transfer Summary form has been devised for this, and consists of the following sections:

- Identifying information.
- Diagnostic information; Multiaxial diagnosis axes I-V.
- Current medication and any side-effects
- Summary of psychiatric history including any hospital admissions
- Preparation for transfer.
- Future management plan.

This latter section has been devised taking into account good standards of care in Community psychiatry: a condensed version of this follows:

<table>
<thead>
<tr>
<th>Date of first appointment at GP clinic location. <em><strong>/</strong></em>/___ With: _________________________</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>FUTURE MANAGEMENT PLAN:</strong></td>
</tr>
<tr>
<td>Regular appointment frequency:  <strong>GP</strong>  1/52  2/52  1/12  2/12  3/12  6/12  1/1  None regular  Other ______</td>
</tr>
<tr>
<td><strong>Psychiatrist:</strong>  2/52  1/12  2/12  3/12  6/12  1/1  None regular  Other ______</td>
</tr>
<tr>
<td><strong>Case manager:</strong>  2/52  1/12  2/12  3/12  6/12  1/1  None regular  Other ______</td>
</tr>
</tbody>
</table>

Action each appointment:

- Cardinal signs of relapse:
- Any Regular investigations: Frequency:
- Response to non attendance:
- Other identified Contingency plans:
- Contact(s) in event of problem:
- Telephone (03-)

The client is introduced to the general practice with a joint appointment at which psychiatrist, general practitioner and often the case-manager are present. The General practitioner has input into the management plan, and can ensure any amendments necessary for effective implementation of the plan in the General Practice context are made. The clarity of this exposition of management plans was what led to the
development of the idea of comparing intended with actual management as an index of quality of care.

**Development of management plans in the Area Mental Health Service Setting**

Within the AMHS setting, the process of development of management plans differs. The study as described above extended across five different AMHS settings, introducing a degree of variability. However there are some general comments that can be made based on general Victorian mental health services policy. All clients according to these policies should have a developed Individual Service Plan (ISP) which is reviewed regularly in multidisciplinary discussion. The format guidelines for this are however somewhat different. The format tends more towards a problem list with a statement that these problems are a proper focus on attention, rather than necessarily a specific statement of clearly operationalised commitments as described above within the CLIPP program.

**Aims**

**Overview**

The overall aim of this project was to assess whether care delivered to patients with severe mental illness in the context of shared care arrangements accords with good standards of clinical care. The criterion for evaluating the care for this aspect of the overall research program was whether the management plans as intended for the individual client were complied with in delivery through the medium of whatever their specific service care setting was. The comparison standard against the CLIPP program was intended to be reference to the prevailing standards in local comparable mental health service settings.

**Research Hypotheses**

1. Plans for continuing management identified at the point of entry into shared care will be well complied with in the context of a continuing shared care project.
2. This level of compliance will be comparable to standards similarly measured in an area mental health service.

**Methods: Trialing a project evaluation approach to clinical management in the mental health care setting.**

**Applying CIPP TO CLIPP – original proposal**

The initial project application for this grant specified that we would employ a project management methodology to clinical process in an attempt to identify the degree of adherence to intended management plans achieved in the GP Shared Care setting. The logic for this part of the program involved an adaptation of the CIPP (Context-Input-Process-Product) model of general program evaluation. Within this model, intended inputs can be compared with observed inputs, intended processes compared with observed processes, and intended product compared with achieved product. Out of all of these comparisons emerges something like a comprehensive picture of the
interaction between input processes and products within the program, and the extent to which there are shortfalls against intended practice through any of these.

Within the initial project proposal the opportunity to do this was based in some good measure upon the extent to which within the CLIPP program management through the transfer summary was articulated in terms of set of very tightly defined tasks with identified recurring intervals. These represent clearly committed and operationalised levels of inputs and process. The aspiration through the initially submitted protocol was that we would be able to look at relative attainment or otherwise of these levels of inputs and processes, then make an absolute judgement about the acceptability of the standards achieved.

The concept of fidelity in clinical management, and its assessment

The concept of this research enterprise derived from project management methodologies, as introduced above, and within which the degree to which a project delivers its intended inputs and processes is a critical factor in understanding outcomes. However there is a related concept in assessment of different clinical service models, being that of fidelity to models. In this respect the current study can be viewed as an attempt to consider the fidelity of management delivery to individualised service models as set out within CLIPP transfer summaries or ISPs.

Modification in response to reviewers

Our initial project proposal was countered with response from reviewers that if we were engaging in this in a GP Shared Care setting, we should also do the same or similar exercise within the Area Mental Health Service setting so that there could be some comparison of general standards achieved across the two care settings. Accordingly the history of the development of the funding for GPEP 518 is actually that a program application firstly was submitted which specified collecting the comparative input and process evaluation data only in the shared care group, reviewers commented that this would be desirable also to do in an area mental health service group, the research team took on the task of doing this, with out best estimate at the time of the cost implications, which did result in allocation of further funds to the program.

Operationalising the process evaluation methodology

As outlined in sequential reports, this study team then proceeded to operationalise this process. One of the principles of this was that if there was going to be comparison of the two methodologies then we should seek to do this by making these sets of data de-identified. Hence, and as described below, we engaged in the process of development of comparative process evaluation which we hoped could be blinded to the treatment condition of either Area Mental Health Service care of GP Shared Care. To this end we developed the idea of a Context Independent Management Plan (CIMP) and a Context Independent Activity Summary (CIAS).
Context Independent Management Plans

The intent was that we prepare for each patient engaged in the study, a management plan that can be seen as context independent. That is to say, an expert scrutinising the plan would be unable to determine from the description of the actions that it had been delivered either in a general practice setting or in the Area Mental Health Service setting. As such there needs to be certain conventions regarding how staff are referred to and conventions regarding the description of actions within the management plan. They formed a data pool described as the ‘Context Independent Management Plan’ (CIMP). We addressed the task of capturing these data from records in the context of the general practice shared care setting and also in the Area Mental Health Service setting, preparing a context independent management plan from each of them.

This required slightly different processes, as the management plan formats are different in the two settings. The transfer summary in the general practice setting is already very close to the format of the intended Context Independent Management Plan, whereas the individual service plan used in the Area Mental Health Service is somewhat different. We established and tested a protocol with case managers which enabled us to create a Context Independent Management Plan which was as closely comparable as possible to that to be found in the general practice setting.

Context Independent Activity Summaries

We now move to the clinical audit of management. This was approached through the preparation of the record known as the Context Independent Activity Summary (CIAS). A large format diary sheet was used to enter, sequentially, information from case notes supplemented with interviews with staff. Hence the CIAS synthesised information both from the case notes and also from the interviewers with clinicians to record the activities actually delivered.

Process evaluation – review of management plans and activity

The task then was for members of the team taking the position of expert reviewers, to scrutinise these two documents, the Context Independent Management Plan (CIMP) and the Context Independent Activity Summary (CIAS), and make ratings of the degree of agreements between them. We tested out various paper print out and electronic formats. The initial concept of using computerised diaries to collect the material proved unwieldy, particularly trials of attempts to carry out comparisons between the CIMP and CIAS data showed that this format was not efficient for this process. Instead paper versions were created for both of the data elements.

The intent has been that it would be possible for the rater to determine for each specified month, whether the management plan can be seen as having failed or not on a series of particular dimensions. This in turn would then enable us to feed this data, a combination of definable quantitative observations and more qualitative impressions, into our statistical analysis in the form of dates of failure, which could form the basis for a comparative survival analysis of the two groups. This could be supplemented with simple proportional data around the time within the two year follow-up period.
that management was complied with. After considerable discussion, the dimensions of desirable management were conceptualised as:

- continuity of care
- medication inputs
- medication monitoring
- symptom monitoring
- social functioning monitoring
- psychological interventions
- social interventions
- responsiveness to negative clinical indications.

**Conduct of the study**

**Data collection and collation.**

Research Field workers, (including GP, IB, LJ) collected the data from casenotes. In the case of the CIMP data, where the intent was unclear from AMHS casenotes, further clarification was sought from Case Managers. For the CIAS data, and in the case of GPs where notes were relatively sparse, the data sources of casenotes were supplemented with direct interviewing by senior researchers (DB, GM). The exercise of data collection proved very time consumptive, and often the total data collection for this aspect of the project alone might require, for an individual subject, up to 1-2 days of researcher time.

Data sets were collected on 40 cases in each of area mental health service and GP care.

Following the collection of these various data sets, we commenced the process of comparison.

**Contrasting experiences of data collection**

The process of data collection proved extremely onerous particularly in the Area Mental Health Service Group. Within the GP Shared-Care Group, the identified management plans are extremely clear, and the conversion between the identified the transfer management plans and the context independent management plan is direct and clear. In the GP Management situation, case notes are extremely sparse. General practitioners mainly speaking record significant positives only. The note taking is quite minimal. This would in Area Mental Health Service setting be typically characterized as denoting very poor practice and limited activity, however the reality of general practice is that much of what goes on is not recorded, but rather the GP will record significant pivot points in management of highly significant novel observations. We attempted to supplement the material with guided interviews in the General practitioners activities, and this did provide some supplementary information. In the Area Mental Health Service, it was very difficult to find for many clients a management summary that approached anything like the degree of clarity of that in the CLIPP transfer patients. Many clients had no identifiable management plan recorded in notes at all. Where they did, this was usually in the form an ISP as
introduced earlier, and which bore little resemblance to the kind of highly structured and detailed commitment made in the CLIPP management transfer summaries. Typically the individual service plan identified a series of problems, and advised that attention be given to these problems. Occasionally some specific tasks were identified and operationalised, but this was unusual.

In contrast to the General Practice setting, in the Area Mental Health Service setting there was a high density of case notes, including highly detailed accounts of much of the work. In this context the Context Independent Activity Summaries were voluminous, and carried large amounts of evidence of activities done and time invested.

The relative asymmetry of the resulting data set is illustrated in tabular form below:

<table>
<thead>
<tr>
<th>Data quality</th>
<th>Management plans</th>
<th>Activity summaries</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP Shared care</td>
<td>+++</td>
<td>+</td>
</tr>
<tr>
<td>AMHS care</td>
<td>+</td>
<td>+++</td>
</tr>
</tbody>
</table>

Various of us; (CH, DB, GM), have invested large amounts of time attempting to code this very disparate and complex qualitative data set. The initial vision was that we would code the identified tasks over a number of dimensions, as described above, then code the activity observed on those same dimensions. We would be able to identify points which the activity ceased, and then apply survival analysis to the data to ascertain the characteristics of the “survival” in positive aspects of management of clients/patients in the GP shared care setting.

This was always going to be a complex exercise, however it has proved more than usually challenging as a research endeavour, and has been the source of much of the delay in finalising the reporting of this work program.

Coding much of the data is very difficult. There is a profound asymmetry in the data set as can be seen from the table.

- The GP Shared care patients have extremely clear context independent management plans, but their context independent activity summaries are sparse, and are most variables if one if holding true diligence to the findings in the data set, there is a high level of missing data.

- In relation to the Area Mental Health Service cases, the Context Independent Management Plans are generally relatively vague, often inferred from documentation that was not structured towards the end of producing such a clear management plan, and very hard to rest much in a way of a sense of validity upon. In contrast, the Context Independent Activity Summaries carry high volumes of information about activities actually engaged.

In summary, in the GP setting we have clear management plans but unclear activity data, in the Area Mental Health Service settings; we have unclear management plans, and very clear activity data.
Delay in analysis

This has generated a problem of coding which we have wrestled with for a couple of years. The unsatisfactoriness of the process has meant that we have made slow progress on the coding of these data. In turn as we have explored the coding we have encountered a number of unanticipated complexities in the data which have required us to revisit the coding manuals. This exercise then has strung out over a long period of time and we now find ourselves having collected data a year or more ago, and in the intervening time, we have revised some of the ideas about the coding manual.

We have reflected on this and the two of us mainly with the role of concluding this aspect of the work feel that all of the data needs to be revisited, and recoded within a narrow time span with a coding manual. We’ve now operationalised the coding manual and we do have a plan in place for concluding the collection of these data. Rather than have it compete within the time constraints of us as senior researchers, we believe that with appropriate supervision, senior doctoral clinical psychologists would be able to manage this task now that we have a well operationalised coding manual. This approach will enable us to revisit all the data, and code it within a similar framework. We estimate there is at 100-150 hours of work to do in completing this task.

It is intended to fund this out of our own accrued research funds. In terms of the funding through GPEP 518, we have already expended very substantially more staff time and input on this part of the project than was allotted for within the original grant. Although we are hopeful that we will be able to conclude this reporting, and we now believe we have an action plan that will secure this by the end of the year, it is not realistic to close this in relation to this project.

Concluding this work, and concluding reporting to GPEP

Unfortunately then for the purposes of the reporting of GPEP 518 we have to regard this task as unsatisfactory in its conclusion. Simply, the task, and particularly as we operationalised it, was something we very much underestimated. We believe it can be concluded however not according to the original plan, and not within the span of delivery of this already very overdue report. We do believe however that this will prove to have been a useful exercise, and once the project reporting is concluded we hope the way will be clear for us to further work on these data with a view to putting journal papers into circulation that will share the interesting and potentially important lessons to be learnt from the development of this quite novel approach to assessing the quality of clinical care.

Priorities for journal publication

Our current priorities in relation to this are 1) writing a methodology paper describing our experience with this and the problems encountered 2) continuing to complete the data to be able to produce a further paper which presents what is available as an outcome of this process.

Once this is done we will explore any possible relations between this dataset and the other variables within the program.
We believe that this investment from GPEP will come to bear fruit in the course of some further understandings about how one might employ project management methodologies to the evaluation of clinical practice, but the conclusion of this task, the complexity of which we grossly underestimated, cannot be achieved within the bounds of the funding available.

**Concluding process evaluation with GPEP**

Hence this final report for GPEP 518 is presented without conclusive data on the process evaluation. We believe that the accompanying clinical outcome information represents a very substantial body of work and the outcome of a monitoring process that advances our understanding of GP shared care. We will be very happy to share future publications derived from the material within this report, and we are confident that other workers in the field will find the insights from this exercise of use.
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