

Scottish Schizophrenia Outcomes Study



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1. Executive Summary

Background

There has been much debate in the National Health Service (NHS) over the past ten years regarding the measurement of outcomes in mental health service settings. Historically, outcome measurement tools were almost exclusively used in specific research studies and not in mainstream routine clinical practice. The Scottish Schizophrenia Outcomes Study (SSOS) was commissioned by the Scottish Executive Health Department as a national demonstration project, at a time when the Clinical Standards Board for Scotland¹ introduced an evidence-based set of standards for the treatment and care of people with schizophrenia (the Standards, CSBS 2001). The introduction of the Standards across Scotland provided a unique opportunity to pilot outcome measures that might assist healthcare teams and practitioners assess the clinical effectiveness of the care they provide. This clinical effectiveness project aimed to assess the clinical outcomes and care for people with schizophrenia receiving NHS care over a period of 3 years, during the period when National Standards for Schizophrenia were being implemented.

Methodology

The design utilised was a prospective naturalistic observational study and was carried out in 4 distinct phases over almost 4 years. The study began in January 2001 and ended in November 2005. All NHS organizations in Scotland agreed to take part in the study (albeit to varying levels of commitment), with only the State Hospital declining to participate. Non-statutory organisations who agreed to participate in the study included the Scottish Association for Mental Health (SAMH) and the Richmond Fellowship (national mental health charities and service providers). The National Schizophrenia Fellowship (Scotland) participated through representation on the Project Advisory Group.

Seven hundred and forty-eight keyworkers (mental health professionals with a caseload of people with schizophrenia) were recruited and, following attendance at a dedicated training event, recruited participants into the study. The study coordinator was assisted within local organisations in the recruitment and training of keyworkers by members of a National Advisory Group. Participants had to be aged 18-65 years and have an ICD-10 F20-29 diagnosis. One thousand and fifteen people with schizophrenia were recruited into the study and almost eighty percent were successfully followed up with annual assessments over a two year period. The cohort was recruited from across Scotland and included a representative sample from every Health Board area.

Findings

SSOS has provided an annual national 'snap shot' of services, interventions and outcomes in people with schizophrenia over four years. Although some trends appear positive, there are areas of concern e.g. uptake of treatments other than medication and participation in employment or training.

SSOS has clearly demonstrated over a three year period that in a representative sample of people with schizophrenia attending the NHS in Scotland, it is feasible to routinely collect mental health outcomes data. The project has demonstrated also that it is feasible to incorporate service user assessments of need into routine practice.

¹ The Clinical Standards Board Scotland was amalgamated into NHS Quality Improvement Scotland (NHS QIS) in January 2003

Furthermore, the keyworker clinicians who participated were almost all positive, not just about feasibility, but also about the clinical utility of information collected in SSOS.

Conclusions/Recommendations

SSOS recommends that standard and validated outcome measures are incorporated into routine clinical practice across mental health services. As a minimum, a core set of assessments, including a clinician rated measure and a service user led assessment of need, should be used. It is further recommended that the key to successful implementation of outcome measures within the mental health service is through local ownership, and the development of Board wide service implementation strategies. Clinicians will only continue to use outcome measures that have relevance and utility for improving patient care.

SSOS has demonstrated that expert training is a requirement for the introduction and successful implementation of outcome measures. Professional training in the use of outcome measures has resource and support implications at both local and national levels if implementation strategies are to be achieved. National Clinical Information Systems and Information Technology (IT) are presently under utilised in the collection and reporting of mental health outcomes data throughout Scotland. If outcome measures are to become integral to clinical practice, it is essential that they are further developed and utilised for reporting of information to clinicians and service users and for benchmarking for service managers, planners and commissioners.

Evidence from SSOS clearly demonstrates that health outcomes for people with schizophrenia have improved over the time-course of the study. However, it is clear that the Clinical Standards for Schizophrenia have not been fully implemented throughout Scotland. National Clinical Standards can therefore only in part have had a causal relationship to improved health outcomes in the project. Significant factors may also include improved clinical services, improved training for health professionals and support from user and carer organisations in the voluntary services. It is anticipated that in the future, Integrated Care Pathways will become established to deliver and provide evidence for the implementation of appropriate standards of care (Delivering for Health 2005).

In order that a consensus view can be reached of how the implementation of outcome measures can be taken forward across Scotland, SSOS recommends that the findings from this study are discussed at a national symposium, hosted by NHS Quality Improvement Scotland.

References

Clinical Standards for Schizophrenia (2001) *The Clinical Standards Board for Scotland*. ISBN 1-903766-01-X.

Delivering for Health (2005) *Scottish Executive Health Department*. Edinburgh: Scottish Executive ISBN 0-7559-4835-1.

2. Introduction

2.1 Outcome assessment in mental health

Despite considerable research interest in the last 20 years, outcome measures for assessing clinical effectiveness in mental health have only been used systematically in routine clinical settings to a very limited extent. There are a number of reasons why this has occurred. Firstly, there has been a lack of consensus about which outcome measure to use. Much research effort in recent years has been limited to addressing the reliability and validity of a variety of different scales rather than the utility of such measures in routine practice settings (Naji & Sheldon, 1993). Moreover it has become increasingly evident in recent years that the outcome measures used in *efficacy studies*, for example of medication or of psychological treatments, have more limited relevance to questions of *clinical effectiveness*. For example ratings scales such as the Positive and Negative Symptoms Scale (PANSS, Kay 1986) are widely used in efficacy studies, but are less appropriate for use in normal clinical settings. Whilst such scales may have a place in the controlled conditions of efficacy studies in carefully selected diagnostic groups, there is growing recognition that more generic and pragmatic outcome measures need to be developed to assess effectiveness in everyday clinical settings (Adams & Hunter 1998).

During the 1990s the Clinical Resource and Audit Group (CRAG) in Scotland was responsible for promoting the development and use of clinical outcome measures in practice. The importance of outcome measures was recognised in the Framework for Mental Health Services in Scotland (1997) (the Framework) as the means by which questions can be asked about the effectiveness of interventions in changing for the better the health status of people with mental health problems. The Framework identified the need to assess clinical, functional and process of care outcomes from the perspective, not only of mental health professionals, but also from the perspective of people who use services. Outcome measures such as suicide or mortality rates have only limited relevance to most people using services and are of limited value to clinicians and mental health teams in working with service users to assist their recovery.

The Framework document also alluded to recent initiatives in outcome measurement including the Health of the Nation Outcome Scale (HoNOS) (Wing et al 1996) and service user centred instruments such as the Avon Mental Health Measure (Avon) (Le Grande 1996). The introduction into clinical practice of service-user generated scales was described in the CRAG Working Group (1996) on Mental Illness report 'Outcome Measures in Acute Psychiatry'. The CRAG report recognised that any useful outcome measure would require at least the following four features: reliability, validity, sensitivity to changes in health that are *clinically important or meaningful to patients*, and lastly have utility and ease of use in normal clinical practice. This report also recommended that the views of people who use mental health services must be incorporated into the measurement of outcome. These issues were addressed by Naji and Sheldon (1993) who list a number of aspects of acceptability, including the need for measures to be perceived as relevant by patients.

In England, the Mental Health National Service Framework (1999) advocated the introduction of HoNOS into routine practice. Following a number of national pilot studies, Fonagy et al (2004) from the Mental Health Outcomes Measurement Initiative further recommended a national programme of HoNOS implementation throughout mental health services in England. HoNOS is designed to be rated by keyworkers on information gathered from patients and other sources during clinical assessment, rather than self-reported by patients. In a recent study from Northern Ireland, HoNOS was

assessed over time and although useful, this was limited by how well informed clinicians were (McClelland et al 2000). The 'Scottish 700 Study' also showed that HoNOS could be useful in clinical settings, but a key reservation was concern about its failure to reflect the service user's perspective (Hunter et al 2004).

2.2 Involving service users in measuring outcomes

Most outcome measures in mental health, like HoNOS, are clinician, rather than service user centred. Sainfort et al (1996) and Hunter et al (2004) found that, although patients and clinicians tend to agree on clinical issues, such as symptoms and functioning, social aspects were often emphasised as more important by service users.

In Bristol, this difficulty was overcome by service users, clinicians and local academics collaborating to develop the Avon Mental Health Measure (Avon) (Le Grande 1996). Recent research in Scotland has established the validity of Avon from the perspective of both service users and clinicians (Hunter et al 2000). In this study, involving almost 700 service users and their keyworker clinicians, 90% of clinicians and patients involved thought that Avon was the instrument with more clinical utility when compared to another ideographic scale. The results suggested strongly that Avon would not only fulfil the criteria for a suitable outcome indicator described in the 1996 CRAG report, but would also have utility in practice to assess the clinical effectiveness of care received by people affected by schizophrenia. Unlike other outcome measures (e.g. HoNOS), Avon is self rated by individuals with support from their clinician. Avon may help encourage an improved alliance between the clinician and service user. By facilitating individuals with schizophrenia and other mental health problems to articulate their concerns (i.e. their mental health needs), a shared health agenda is established between service user and clinician. This has advantages for ensuring that relevant needs are addressed and concordance with treatment improved.

In conclusion, there is evidence from the Scottish 700 Study, that Avon satisfies criteria required of an outcome measure in mental health, and importantly puts the needs and concerns of the individual service user at the centre of the assessment process. The development of useful outcome measures for mental health services requires that account is taken of two complementary perspectives, that of patients and clinicians. In this study we therefore decided to use Avon alongside a clinician derived measure such as HoNOS or CANSAS (Camberwell Assessment of Need Shortened Assessment Scale) (Camberwell 1999).

2.3 Clinical standards for schizophrenia

The Clinical Standards Board for Scotland¹ (CSBS) introduced an evidence-based set of standards for the treatment and care of people with schizophrenia (the Standards, CSBS 2001). Eleven standards were introduced across all NHS organisation areas in Scotland for the care of people with schizophrenia from January 2001 onwards. An audit of performance against Standards 2 and 7-11 was carried out during March-November 2001, and results published in March 2002 (National Overview 2002). In a second phase, NHS Quality Improvement Scotland (NHS QIS) carried out an audit of the five remaining Standards, 1 and 3-6, and results were published in June 2004 (National Overview 2004). The introduction of the Standards across Scotland provided a unique opportunity to pilot outcome measures that might assist clinical teams assess

¹ The Clinical Standards Board Scotland was amalgamated into NHS Quality Improvement Scotland (NHS QIS) in January 2003

the clinical effectiveness of the care they provide. This clinical effectiveness project aimed to assess the outcomes of care for people with schizophrenia receiving NHS care over a period of 3 years during that period when National Standards for Schizophrenia were being introduced.

3. Aims and Objectives

The overall objective of this project was to assess the potential impact on care/treatment for people with schizophrenia, of the introduction of the national Clinical Standards, through the systematic collection of clinical, pragmatic and user-centred outcome measures. The specific aims of the project were as follows:

1. To establish the routine collection of user-centred and pragmatic clinical outcome data for people with schizophrenia living in different areas of Scotland.
2. To assess the feasibility of routinely collecting outcome data throughout the mental health service in Scotland.
3. To describe the pattern of outcomes across the areas at three time points (baseline, 12 months, 24 months).
4. To assess the impact of the Clinical Standards for Schizophrenia on clinical effectiveness.
5. To describe the resource use associated with routine collection of outcome data throughout the mental health services involved, and the issues this raises with respect to the implementation of the Standards.

4. Methodology

4.1 Project management

The project was managed on a day to day basis by the Grant Holder and a Project Coordinator. The core research team included a nurse researcher & administrative assistant at different stages of the work plan. A website was developed in the early stages of the project www.schizophrenia-outcomes.org. A Project Advisory Group (PAG) was established to advise the research team and the group met regularly. The PAG consisted of the co-applicants, a representative from the Scottish Association for Mental Health (SAMH), a carer representative from the National Schizophrenia Fellowship (Scotland), a statistician, a health economist, a representative from NHS QIS and consultant psychiatrists from local recruitment sites. A complete list of PAG members is shown in *appendix 1*.

A National Advisory Group (NAG) was also established which consisted of key individuals who were mainly clinical managers with responsibility in each of the recruitment sites for services for people with schizophrenia. These representatives included Clinical Governance/Effectiveness Managers, Service Development Managers, Lead Nurses and Practice Development Nurses. The role of these representatives was to provide a focus for the project in local NHS services and thereby to help drive the project forward within their locality. A complete list of NAG members is shown in *appendix 1*.

4.2 Project design and timetable

The design utilised was a prospective naturalistic observational study and was carried out in 4 distinct phases:

Phase 1 (Baseline)

➤ During the initial phase, feasibility, logistics, Ethics Committee approval, and management arrangements for the project were determined. This phase also included training and education for participating keyworker clinicians, followed by recruitment of participants. Data management systems were developed and baseline data collected. A national meeting was hosted by the Scottish Schizophrenia Outcomes Study (SSOS) where data findings and sharing of practice was disseminated.

Phase 2

➤ Repeat assessments were carried out by keyworkers and participants at 12 months along with the completion of the core data sheet by the keyworker. A second national meeting was hosted.

Phase 3

➤ Refresher training was offered to keyworkers along with Phase 1 and 2 feedback sessions within each of the recruitment sites. Repeat assessments were carried out by keyworkers and participants along with completion of the core data sheet at 24 months.

Phase 4

➤ Data analysis and interpretation; national conference discussion of data; report writing and dissemination

4.3 Extension to original timetable

The project was initially funded for 3 years from 1 January 2002 – 31 December 2004. However, the lead-in time at the beginning of the study was underestimated for several reasons. Firstly, in order to recruit successfully it was agreed with NHS QIS that the study should recruit from all areas of Scotland rather than the 4 sites originally planned. Recruitment could not begin until ethics approval and local research management approval had been granted. In some instances this proved problematic as discussed separately in section 5.11 on Ethical Approval.

Secondly, there was a time lag between obtaining management approval to carry out the study within NHS organisations, and organising meetings and awareness sessions within differing levels of these organisations, before recruitment of keyworkers could take place. For example, following management approval, a time slot would have had to be negotiated at a Clinical Governance Committee meeting to present the study. Once the Committee approved local participation in the study, locality or team leader meetings were organised to present the case for the study. Once this was achieved, awareness sessions at team level took place to speak to individual staff.

These necessary steps took considerable time. As more sites became interested in becoming involved, awareness sessions, recruitment of keyworkers, and keyworker training, were delivered on a rolling basis.

An eight month extension to the study was granted and resourced from within the original budget. In March 2005, in consultation with NHS QIS, the project end date was further extended to 31 November 2005 to enable SSOS to organise a National Conference to help disseminate findings. The total duration of the project was 47 months.

4.4 Recruitment of sites

Letters of invitation to participate were sent to Chief Executives, Medical and Nursing Directors of every NHS mental health service in Scotland, as well as non-statutory organisations, describing the study and asking for their approval to conduct the study within their organisation. This gave information about the purpose of the study and its relevance to the implementation of the National Standards for Schizophrenia. Once management approval had been granted, a series of 65 awareness sessions took place throughout the 19 sites across Scotland explaining what the aims of the study were, why it was being undertaken, what SSOS would require from clinicians, and also what SSOS could offer in return.

All NHS organisations agreed to take part in the study (albeit to varying levels of commitment); only the State Hospital declined to participate. Participating NHS Organisations included:

Ayrshire & Arran	Borders	Dumfries and Galloway
Fife	Forth Valley	Glasgow
Grampian	Highland	Lanarkshire
Lomond & Argyll	Lothian	Orkney
Renfrewshire & Inverclyde	Shetland	Tayside
West Lothian	Western Isles	

Non-statutory organisations who agreed to participate in the study included the Scottish Association for Mental Health (SAMH) and the Richmond Fellowship (national mental

health charities and service providers). The National Schizophrenia Fellowship (Scotland) participated through representation on the PAG.

4.5 Recruitment of people with schizophrenia to the project

Initially it had been intended to recruit a target of around 2000 people with schizophrenia, but due to the nature of the illness, it was recognised that this would be difficult from only 4 centers. Moreover, the National Overview of Schizophrenia Standards (CSBS, March 2002) indicated that approximately 9000 people with schizophrenia were in contact with secondary mental health services in Scotland. Using a sampling frame, the aim was therefore to recruit at least 900 participants, i.e. 10% of those receiving care from NHS mental health services. The original protocol was amended to reflect the above points and approved by the Multicentre Research Ethics Committee (MREC) in March 2003.

It had been intended to utilise Trust information systems to identify all patients with an ICD-10 F20-F29 diagnosis (WHO 1992), however following a scoping exercise, it became clear that the vast majority of participating centres did not use Electronic Patient Records, nor could they identify all their patients with an ICD F20-29 diagnosis. This deficiency of available data and data systems within mental health services in Scotland was highlighted in the CSBS National Overview (2002) and in the more recent National Health Services Assessment (Grant, 2004). It was therefore necessary to rely on keyworker clinicians to identify patients on their caseloads with schizophrenia. Before inclusion the diagnosis was confirmed with the patient's consultant psychiatrist.

Prospective participants were given an information sheet detailing the study (*appendix 2*) by their keyworker and allowed time to decide if they wished to participate. If they did wish to participate they were then asked to sign a consent form (*appendix 3*). This proved to have a negative impact on recruitment as a number of participants were willing to participate, but not willing to sign consent forms. Only those who signed consent forms were included in the study.

4.6 Recruitment of keyworkers into the study

Keyworkers were recruited on a voluntary individual participation basis. Attempts were made, where possible, to recruit 'teams' in order to enable a multidisciplinary approach to using outcome measures. However, at the time of recruitment, in many sites, community based multidisciplinary teams did not exist, or were just being formed.

A keyworker was any professional working with people with schizophrenia on their caseload. The mix of professionals recruited to the study included: Nurses (83%); Occupational Therapists (10%); Social Workers (3%); Support Workers (2%); Psychiatrists (1%); Psychologists (1%).

Keyworkers who expressed an interest in the study were invited to attend an awareness session in their local area where they were given information about the study and registration forms were completed. In conjunction with the local NAG representatives, a series of local training events were organised and keyworkers were invited to attend a one day training event in the use of the outcome measurement tools.

A Microsoft Access Database (version 2002) was designed to record keyworker registration and training.

In total, 748 keyworkers were registered with the study and 426 remained as active on the database at the end of the study in November 2005. In order to establish the reasons why keyworkers did not recruit to the study, a sample of registered keyworkers (n=130) who did not recruit were asked to complete a questionnaire. Ninety one responses were received and these are summarised below:

- 28% *registered with the study, but did not go on to attend training*
- 23% *attended for training but moved to a new post/left the service*
- 21% *could not recruit due to having no suitable patients (some were from acute settings where patients were too unwell to consent to participate and others from community settings where keyworkers had small caseloads)*
- 10% *had small caseloads and could not obtain consent from patients*
- 8% *following training, could not recruit due to 'time constraints'*
- 7% *following training, went on long term sick leave or maternity leave*
- 3% *cited a lack of management support for using outcome measures/study*

It was assumed at the beginning of the study that problems might be encountered following up participants over a three year period due to movement within localities and regions. However this was not the case, but what was not expected was the turnover of keyworkers. This proved to be a major administrative burden for the coordinator. For example, a keyworker may have recruited 4 participants into the study and then subsequently moved to a new post or left the service. Those participants might then be allocated to 4 new keyworkers. If those keyworkers were not registered with the study they would require individual training from the study coordinator. In some cases newly recruited keyworkers also moved on.

Overall, 428 participants had one or more keyworker change throughout the study. This under reports the actual number of changes as some keyworkers elected to follow-up participants who had moved out of their service area. While some changes in keyworker were anticipated, e.g. when a participant was discharged from an inpatient setting, it was also noted that some participants had changes of keyworker within their community setting. This may be an area for future study as such changes may impact on mental health outcomes, and have implications for the use of outcome measures in practice.

By year 3, when a change of keyworker took place and those new keyworkers were registered with the study, the majority did not require training by the coordinator as this was being cascaded locally within their team setting. This may reflect increased routine use of outcome measures within clinical teams.

A questionnaire was sent to a sample of keyworkers at the end of the study period to establish if they would continue to use outcome measures in routine practice. Of the sample who responded (n=142) only 35% said they had used outcome measures prior to becoming involved in SSOS, but 90% of respondents said they would continue to use them when the study finished. The results are detailed in Appendix 4.

4.7 Training

72 training events were delivered throughout 2002 and 2003 to a total of 592 keyworkers. These events involved keyworkers attending a full day event which covered an introduction to SSOS, discussion regarding the clinical standards for schizophrenia along with other national initiatives, and training in the use of the core outcome measurement tools being utilised for SSOS. A typical training agenda can be viewed in *appendix 5*. Five hundred completed training evaluation forms were received

and analysed and a separate report is available from SSOS. Twenty refresher training sessions and local updates were delivered throughout 2003/2004.

Two HoNOS Accredited 'Training for Trainers' days were facilitated by SSOS and this training was delivered by the HoNOS National Training Advisor from the Royal College of Psychiatrists Training and Research Unit. Twenty-eight people attended the training from 9 NHS organisations. This was a valuable resource for SSOS as local accredited trainers were on hand for keyworkers from within their organisation for assistance if required for the purposes of the study. It was also beneficial for participating organisations as most Trainers have gone on to cascade HoNOS training within their own localities.

One refresher HoNOS 'Training for Trainers' day was delivered in May 2005, attended by 19 Trainers.

Sixty-seven keyworkers attended Presentation Skills and PowerPoint training sessions. These were made available initially for keyworkers who were presenting their work at SSOS National Meetings and then later, due to demand, offered to all keyworkers.

4.8 Outcome measures utilised

The core tools chosen by the SSOS for the purpose of the study were HoNOS and Avon. However, where organisations were already utilising an alternative outcomes tool at the time of recruitment they were not excluded from participating. Rather, this was viewed as an opportunity to include other outcome measures within the study and encourage the use of such measures locally. The distribution in the use of the tools was as follows:

- 89% of keyworkers utilised HoNOS and Avon
- 8% utilised Avon and FACE¹
- 2% utilised Avon and CANSAS²
- 1% utilised HoNOS and CANSAS

4.9 Data collection

The data collection form (*appendix 6*) was kept as simple as possible for clinicians to complete both quickly and accurately within their normal clinical practice. Completed data sheets were forwarded by keyworkers to the SSOS Research Centre in Glasgow, where data were checked, cleansed, coded and entered into a single Access database. Data were collected on 1015 participants who consented to take part at baseline.

¹ FACE – Functional Analysis of Care Environments; www.facecode.com

² CANSAS – Camberwell Assessment of Need. Published by Gaskell, London

4.10 Statistical methods

Background

The Robertson Centre for Biostatistics at the University of Glasgow was responsible for statistical analysis. The statistician involved with SSOS from its inception also advised in the data analysis for the Scottish 700 Study, and therefore had experience of working with outcomes (see Hunter et al 2004) and extensive experience of mental health research. The statistician moved to the Centre for Healthcare Randomised Trials (CHaRT), in the Health Services Research Unit, University of Aberdeen in September 2003, where the later analyses were undertaken. SAS 8.2 and 9.1 for Windows (SAS Institute) statistical analysis software was used on all statistical analyses.

Analyses

There were 4 main areas of analysis

- Descriptive statistics at baseline
- Trends over time in outcomes, treatments and services
- Analysis by NHS organisation
- How well were the Clinical Standards for Schizophrenia met?

Descriptive statistics at baseline

The data for baseline (Year 0) characteristics were displayed using histograms. The following variables were summarised

- Location of clinics
- Years since diagnosis
- Current living arrangements
- Psychiatric hospitalisations
- Attempted suicide
- Self Harmed
- Care Programme Approach (CPA)
- Detention under the Mental Health Act (MHA)
- Imprisonment
- Medications
 - Typical and atypical antipsychotics
 - Depot and oral antipsychotics
 - Discretionary (as required) antipsychotics
 - Mood stabilisers
 - Anxiolytics
 - Antidepressants
- Polypharmacy (number of above medications per participant)
- Other Treatments
 - Educational programme
 - Cognitive Behavioural Therapy (CBT)
 - Other Psychological Interventions (OPI)
 - Physiotherapy
 - Family intervention
 - Voluntary services
- Services
 - Alcohol
 - Drugs
 - Forensic
 - Occupational Therapy
 - Psychology
 - Social work

Trends over time in outcomes, treatments and services

For many of the outcome measures and for the various types of medication, the change in these measures over the duration of the project was estimated using statistical models. The raw proportions of all binary outcomes (Yes/No) for psychiatric hospitalisation, detention, imprisonment, CPA, attempted suicide, self harm, in the previous 12 months was first plotted over the 3 time points using a time plot. Using a mixed effects logistic regression model, with subject as a random effect and time as a fixed categorical effect (phase 1, 2 and 3) the Odds Ratio (with a 95% confidence interval [CI] and associated P-value) of e.g. psychiatric hospitalisation at phase 2 vs. phase 1 and at phase 3 vs. phase 1 was estimated. An autoregressive AR(1) correlation structure across the years was assumed and the generalized estimating equations (GEE) approach was used to fit the model. Phase 2 and 3 were compared using a likelihood ratio test. Finally a number of covariates were introduced which might be predictive of the outcome in question, e.g. psychiatric hospitalisation, to adjust the estimated effect over time found in the first model. The values of the covariates as measured at each phase were used. Odds ratios for covariates which were jointly significant at $P < 0.001$ are selectively reported. These estimates are from the model which adjusts for the full set of covariates, and so are conditional on all the covariates in that model.

For the continuous outcomes such as HoNOS and Avon, the same modeling strategy was employed except the model was a linear regression model with a normal error structure. The covariates comprised: where rated, setting, employment status, age, gender, time since diagnosis, main carer, lives with main carer, lives alone, where currently living, detained under MHA, CPA, suicide attempt, self harm (all in last 12 months), currently detained (MHA), clozapine, discretionary and regular medication (typical, atypical, oral, depot), use of health services/interventions (ECT, CBT, alcohol, drug, forensic, education, housing, voluntary, social work, physiotherapy, occupational therapy). Covariates were eliminated from the model if they were either proxies for the outcome of interest or highly correlated with other covariates already in the model. Full details are available on request.

Analysis by NHS organisation

In order to assess the relative prevalence of outcomes, medication use, and use of treatments and services across the health regions, analyses was conducted in which the expected prevalence of the outcome in a particular NHS organisation was estimated, given their case mix, assuming that the NHS organisation behaved in a similar fashion to the rest of Scotland, excluding that NHS organisation. This was done for each NHS organisation in turn, using a statistical model (the same type of models described in the section trends over time above) that linked covariates to the outcome of interest, using data from the rest of Scotland excluding that NHS organisation. The parameter estimates summarizing the joint relationship of important covariates to this outcome were saved, and applied to each individual's covariate profile in that NHS organisation to estimate the expected outcome. These expected outcomes were then aggregated across all individuals in that NHS organisation, and an approximate 95% confidence interval around that aggregated expectation was calculated.

This was then repeated for each NHS organisation in turn, and the difference between the observed and expected behavior displayed graphically. The NHS organisations were anonymised for this plot.

How well were the Clinical Standards for Schizophrenia met?

The extent to which the Clinical Standards for Schizophrenia were met was reviewed, using data published by NHS Quality Improvement Scotland. The 11 standards comprised 72 essential criteria. Using the Standards definition of 'fully met', for each NHS organisation the proportion of these 72 criteria that had been fully met was calculated. A mean was then calculated and a 95% confidence interval across all the NHS organisations. Then for each standard, the proportion of the criteria that constituted that standard (between 4 and 9 criteria made up individual standards) that had been fully met within each NHS organisation was calculated. A mean for that standard with a 95% confidence interval was then calculated.

4.11 Ethical approval

Muticentre Research Ethics Approval (MREC) was sought and provisional approval received on 23 January 2002. Following the revision of the participant consent form and information sheet full approval was granted in April 2002.

As was required under the Ethics Authorisation process in operation at the time (now superceded) full applications to each Local Research Ethics Committee (LREC) for each of the participating sites were then submitted. All submissions were approved, although responses to the applications varied widely across the country. The full process of obtaining MREC, LREC and Local Research & Development Management Approval took almost 7 months.

A revised protocol was approved by MREC in March 2003 detailing the change from 4 participating sites to 19. As a result the study was undertaken in every health board area. One important consequence of this change was to increase the complexity associated with the challenge of describing the resources associated with the routine collection of outcome data (Aim 5). Within the given resources it has not been possible to go beyond describing the resources used to carry out SSOS (Section 5.12). A comprehensive health economics appraisal of the SSOS project is planned with colleagues at the Universities of Glasgow and Aberdeen.

4.12 Costs associated with the project

The total cost of the grant awarded was £227,546.12 which covered the costs of carrying out the project; £12,500 of this grant was used towards national conferences. Additional support for the project nurses amounted to approximately £35,500. Project and National Advisory Group members, along with keyworker staff time, was allocated from within existing NHS resources.

5. Results

5.1 Description of SSOS cohort at baseline

All NHS organisations in Scotland providing mental health services agreed to take part in the study apart from the State Hospital, Carstairs (see Figure 1). Of the 1015 subjects recruited to the study, almost three-quarters were male (70%) and outpatients.

The ICD-10 diagnosis range of recruited participants was F20.0-20.9 (92.5%); F21.0-24.0 (1.7%); F25.0-25.9 (5.3%); and F26.9-29.5 (0.5%). The mean age of the cohort was 43 (males 42 and females 44) with a range of 18 to 78 years. Thirteen percent (133) of the cohort had a confirmed comorbid diagnosis of substance misuse at baseline.

Fifty-seven percent were diagnosed with schizophrenia ten years ago or more (see Figure 2) and most of the cohort (862) were not detained, but 4% (42) were detained under the Scottish Criminal Procedures Act, and 11% (107) the Mental Health (Scotland) Act.

Figure 1 - Numbers of participants recruited from each organisation

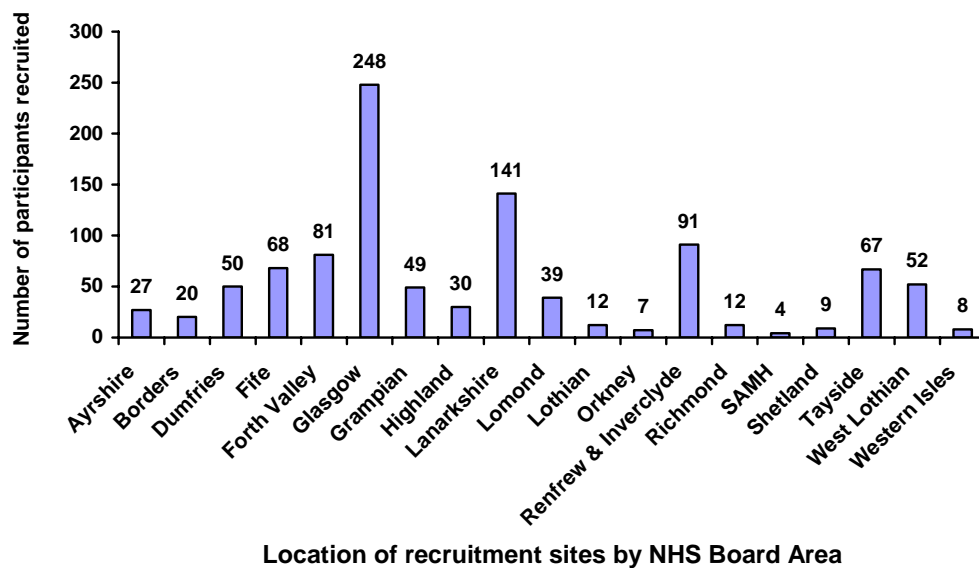
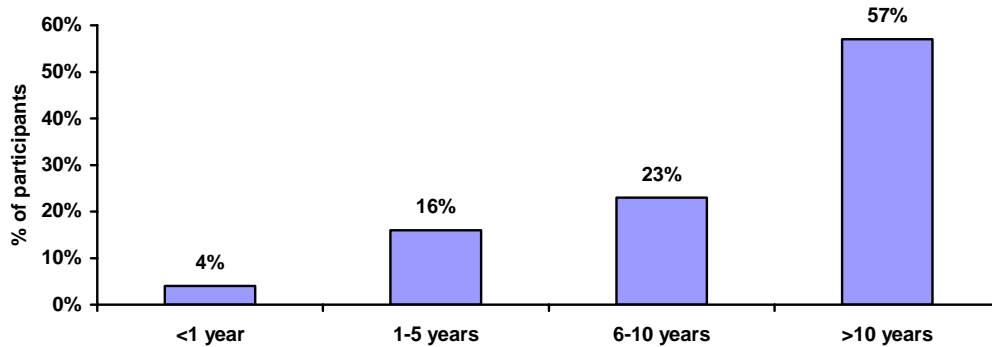


Figure 2 - Years since diagnosis

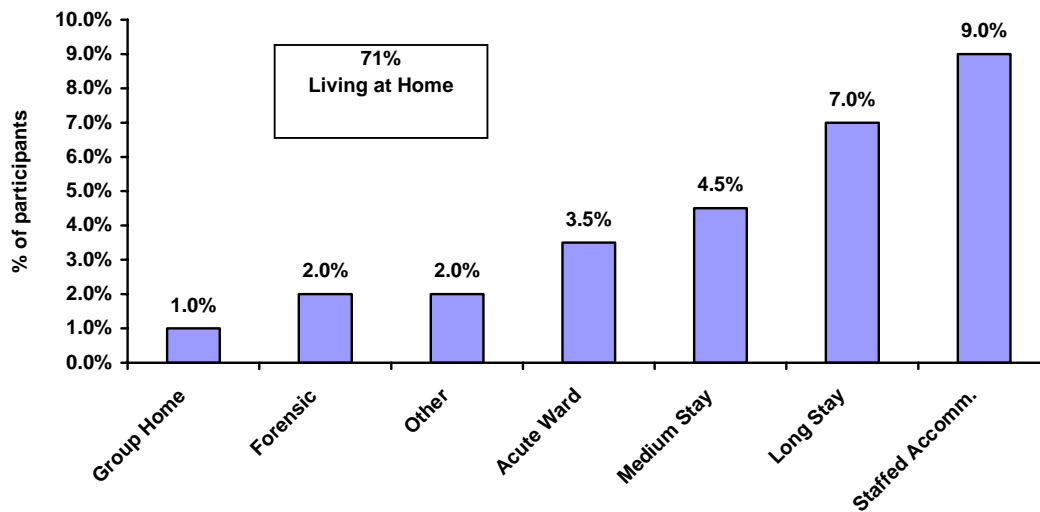


Ninety percent of subjects (916) were currently registered with a GP, 49% (493) were living alone in the community, and 31% (318) were living with a main carer. Seventy-one percent (725) were living at home, while almost 20% (188) were resident within an NHS facility and a further 10% (102) in supported accommodation (see Figure 3).

Only 0.3% (3) were in full-time employment, 1.8% (18) in sheltered work, and 3% (29) in some sort of voluntary work.

Participants were recruited from a number of different settings, 77% (780) from community or out-patient settings and 23% (235) were recruited from in-patient settings.

Figure 3 - Where participants were living at recruitment



5.2 Pragmatic measures of outcomes in the year before baseline

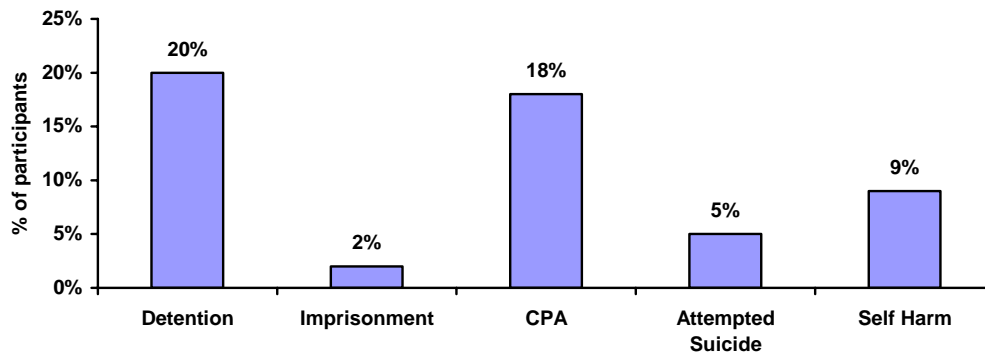
Fifty-nine percent (595) had no psychiatric admission to hospital during the year before recruitment, 22% (224) had a single admission, 6% (65) two admissions and 4% (37) three or more admissions. Nine percent (94) were recruited whilst already in hospital.

Of these admissions, 20% (202) were detentions under the Mental Health Act, while 2% (21) spent time in prison (see Figure 4).

Eighteen percent (187) of the cohort were subject to the Care Programme Approach (CPA), a system of organising care applied to those patients with complex needs. Although CPA is a statutory process wide variations exist in its application across Scotland.

Over the year prior to recruitment into the study 5% (54) attempted suicide and a further 9% (90) were noted to have exhibited some form of self-injurious behavior.

Figure 4 - Other pragmatic outcomes in the year before baseline



5.3 Medication and other treatments/services at baseline

Figure 5 shows the antipsychotic medication being taken at baseline. Twenty percent (205) of the cohort were also taking additional discretionary antipsychotic medication (16% (168) typical; 4% (37) atypical). Other psychiatric medication taken on a regular basis is shown in Figure 6. Thirty percent (304) of the group were taking one medication, with most (70%) taking two or more (Figure 7).

Figure 5 - Regular Antipsychotic medication

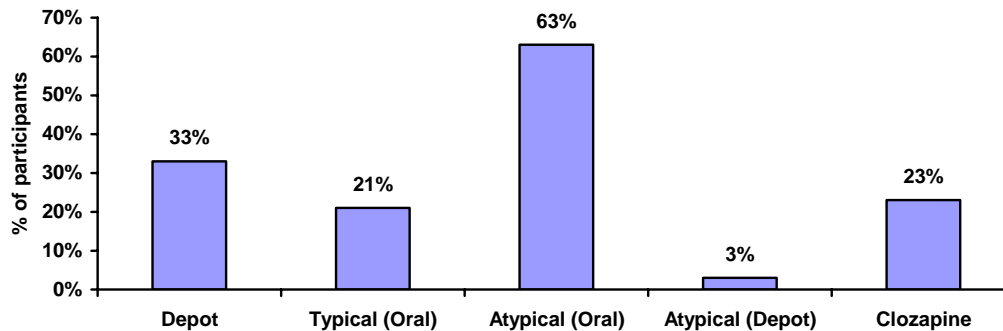


Figure 6 - Other psychotic medication

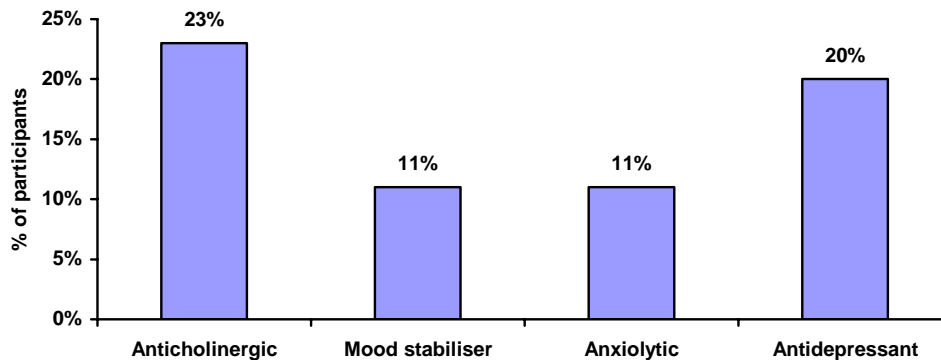
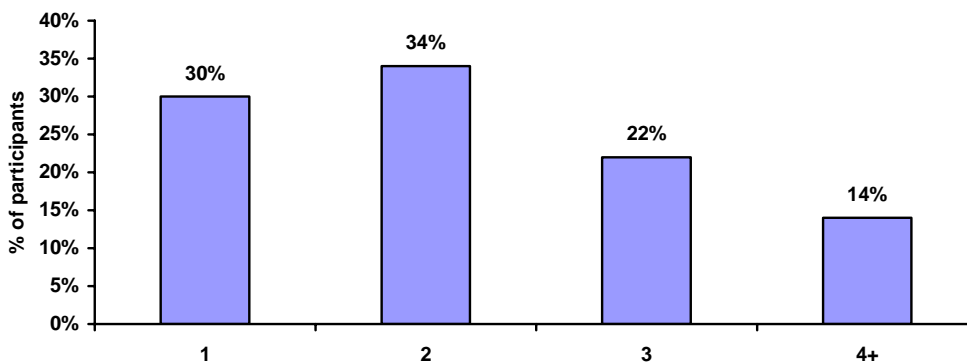
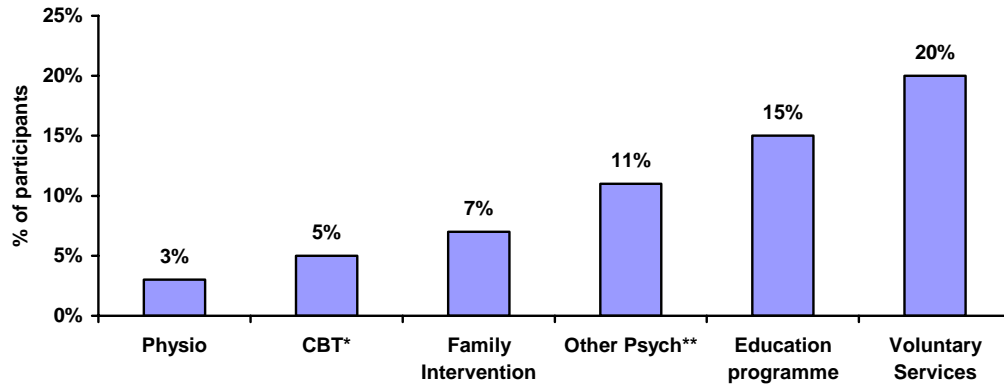


Figure 7 - Number of antipsychotic medications taken at baseline



The other types of treatment received by members of the group in the last year are shown in Figure 8. While 16% (170) had received some form of psychological intervention, most patients had received no other reported treatment (50%). Over the past year only 7% (73) had received input from psychologists, and 36% (366) from social work (see Figure 9); 69% (703) received input from nursing staff and 71% (723) from a psychiatrist at baseline, whilst this increased to 92% (844) nursing and 83% (762) psychiatrist at phase 2. It is suspected that the explanation for this discrepancy is that these two inputs were under reported at baseline.

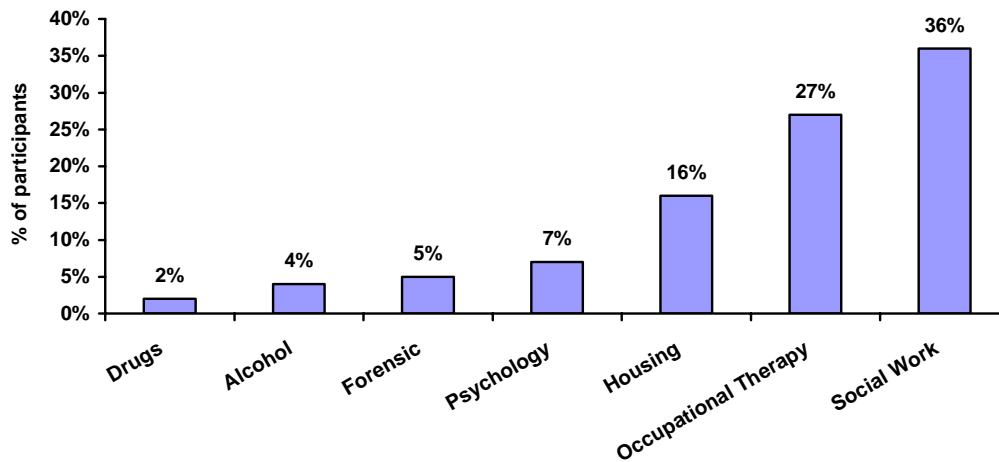
Figure 8 - Other treatments within the last year



*CBT = Cognitive Behavioural Therapy

**Other Psych = Other forms of psychological treatment

Figure 9 - Other services received within last year



5.4 Outcome measures and interventions: trends over time-course of SSOS and modeling of predictors of outcome

Figures 10–26 show the trend over time for outcome measures and interventions at phase 1 (baseline), phase 2 and phase 3.

Full details of the modeling approach for each outcome is given in the Statistical Methods section. For each outcome, a time plot of the raw data is given, along with a table reporting the odds ratios, 95% confidence intervals, and associated P-values from the multivariate logistic regression models (Tables 1–23).

Psychiatric hospitalisation

Figure 10 shows that hospitalisation dropped from just over 41% at phase 1, to just under 30% phase 2, and maintained at that level at phase 3. This equates to a reduction in the odds of psychiatric hospitalisation at phase 2 compared with phase 1 of about 40%, with a 95% confidence interval (CI) of as much as a 53% reduction through to as little as a 22% reduction (odds ratio 0.60, 95% CI 0.47 to 0.78, $P < 0.0001$), (Table 1). Very similar results are found at phase 3 compared with phase 1 (OR 0.71, 95% CI 0.53-0.95), $P < 0.0001$), with no difference detected between phase 2 and phase 3 ($P = 0.24$) (see Table 1).

In terms of the covariates associated with psychiatric hospitalisation (Table 2), a suicide attempt in the previous 12 months is associated with a 233% increase in the odds (95% CI 72% to 545% increase, $P = 0.0003$) and at least one episode of self harm in the previous 12 months is associated with a 191% increase in the odds, 95% CI 83% to 362%, $P < 0.0001$). Similarly admission in the previous 12 months was also significantly associated with Clozapine and the use of additional support services.

Figure 10 – Psychiatric hospital admissions in previous 12 months

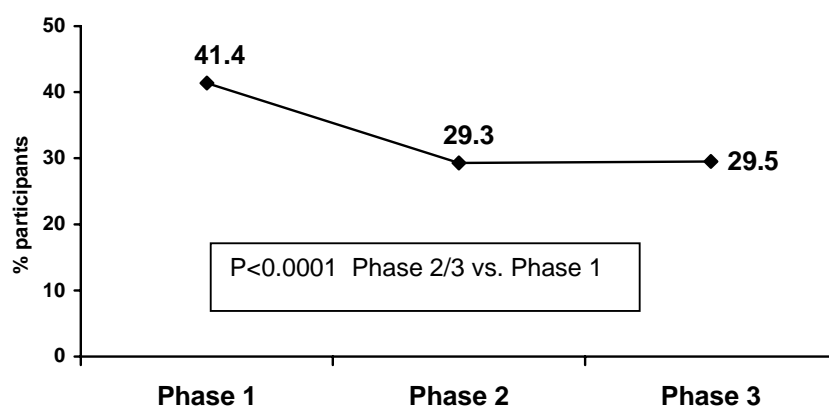


Table 1 - Psychiatric hospitalisation - Odds Ratios (95% CI) by Phase

<u>Contrast</u>	<u>Unadjusted</u>	<u>Adjusted</u>
Phase 2 vs. phase 1	0.61(0.53-0.69)*	0.60 (0.47-0.78)*
Phase 3 vs. phase 1	0.61(0.52,0.71)*	0.71 (0.53-0.95)*
Phase 3 vs. phase 2	$P = 0.75$	$P = 0.24$

* $P < 0.0001$

Table 2 - Psychiatric hospitalisation - Odds Ratios (95% CI)

<u>Contrast</u>	<u>Odds Ratio (95% CI)</u>	<u>P-value</u>
Phase 2 vs. phase 1	0.60(0.47-0.78)	< 0.0001
Phase 3 vs. phase 1	0.71(0.53-0.95)	< 0.0001
Suicide Attempt	3.33(1.72,6.45)	0.0003
Self Harm	2.91(1.83,4.62)	< 0.0001
Clozapine	1.71(1.29,2.28)	0.0002
Additional Services Y/N	1.87(1.44,2.42)	< 0.0001

Care Programme Approach

Use of the Care Programme Approach increased by about 3% over the 2 phases of follow up from about 18% at baseline (see Figure 11), but these increases were not statistically significant. Having a main carer from the local authority or the voluntary sector more than doubled the odds of being on CPA, while the use of any additional services increased the odds by 65% (Table 4). This may reflect the use of CPA as a tool to facilitate multi-agency working in complex cases.

Figure 11- Care Programme Approach (CPA)

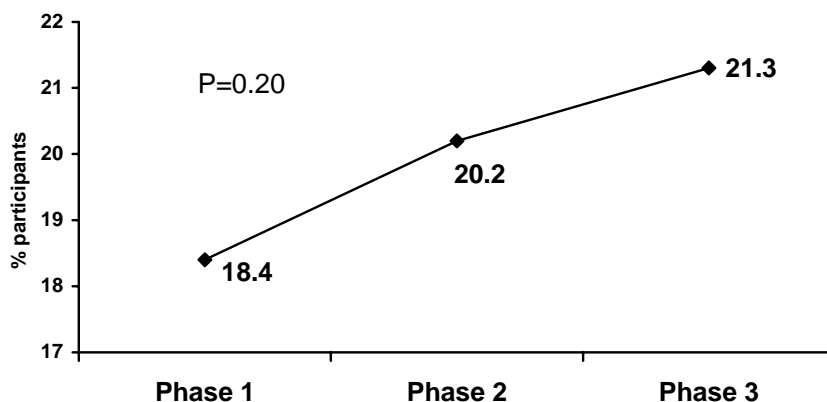


Table 3 - Care Programme Approach - Odds Ratios (95% CI)

<u>Contrast</u>	<u>Odds Ratio (95% CI)</u>	<u>P-value</u>
Phase 2 vs. phase 1	1.08(0.94,1.25)	0.25
Phase 3 vs. phase 1	1.15(0.98,1.35)	0.089
Main Carer – LA/Voluntary	2.27(1.68,3.07)	<0.0001
Additional Services Y/N	1.65(1.33,2.05)	<0.0001

Attempted suicide/self harm

Any attempt at suicide in the last 12 months dropped from just over 5% at baseline to under 3% by phase 2 and less than 2% by phase 3 (see Figure 12). These differences were statistically significant, and equated to a reduction in odds of a suicide attempt of 40% at phase 2 and 64% at phase 3. Older patients were less likely to have attempted suicide (a reduction of 3% in the odds for every year older), and having been detained under the Mental Health Act in the previous 12 months increased by approximately three fold the odds of a suicide attempt having occurred in the last 12 months. Note that as with all of these associations, it is not possible to ascribe causality temporally – for example the first of possibly multiple suicide attempts in the previous 12 months may have come before or after the first of possibly multiple detentions under the Mental Health Act in the previous 12 months (Table 4).

For the outcome of at least one episode of self harm in the previous 12 months, there was an observed reduction of 3% from 9% to 6% from baseline to phase 2, and this level was maintained at phase 3. These changes were statistically significant, and equated to a reduction in the odds of about one third (34%). As with a suicide attempt, age was a negative predictor, with an approximate 5% reduction in odds for every year older. Male gender was also associated with a reduction in the likelihood of self harm, with the odds for males 43% lower than for females (Table 5).

Figure 12 - Suicide Attempt/Self Harm

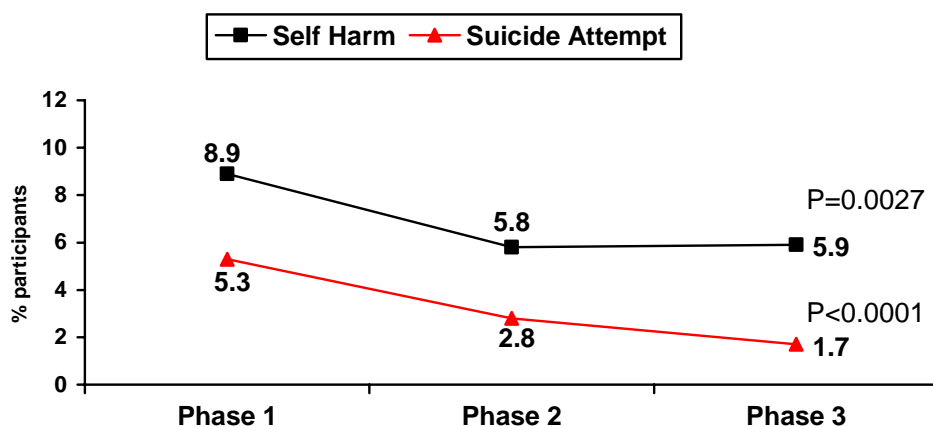


Table 4 - Suicide Attempt - Odds Ratios (95% CI)

Contrast	Odds Ratio (95% CI)	P-value
Phase 2 vs. phase 1	0.60(0.39,0.94)	0.026
Phase 3 vs. phase 1	0.36(0.20,0.67)	0.0012
Age (1 year older)	0.97(0.95,0.99)	0.013
Detention under MHA	3.73(2.32,5.99)	<0.0001

Table 5 - Self Harm - Odds Ratios (95% CI)

Contrast	Odds Ratio (95% CI)	P-value
Phase 2 vs. phase 1	0.64(0.49,0.84)	0.0015
Phase 3 vs. phase 1	0.64(0.47,0.88)	0.0053
Age (1 year older)	0.95(0.94,0.97)	<0.0001
Male Gender	0.57(0.38,0.85)	0.0056

Current legal status

There was a marginally significant trend downwards in the proportion of participants being currently detained under the MHA (from 10% to 9% to just over 7% at phases 1, 2 and 3) (see Figure 13), but after adjustment for covariates these differences were no longer significant. Again, age was a negative predictor, with every year older equating to a reduction of about 4% in the odds of MHA detention. Having a nurse as a main carer was associated with more than double the odds, while having a carer from the local authority or the voluntary sector roughly tripled the odds (Table 6).

For participants coming under the Criminal Procedures Act, there was an apparent drop from about 4% to 3% in phase 2, but this proportion crept back up to the midway point between these two by phase 3. These differences were not statistically significant. Proceedings under this act were almost exclusively confined to men, and were much more likely if the participant was registered with a GP (probably reflecting a proxy for being in the community and therefore able to be subject to the Act). Detention was less likely with increased age (reduction of odds of about 8% for every year older) and the odds roughly quadrupled for those who had been detained under the MHA in the last 12 months (Table 7).

Figure 13 - Current Legal Status

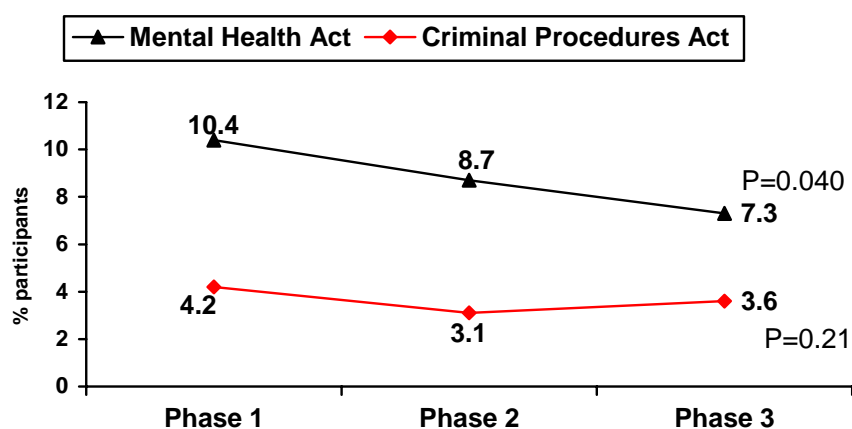


Table 6 - Current Mental Health Act (MHA) - Odds Ratios (95% CI)

Contrast	Odds Ratio (95% CI)	P-value
Phase 2 vs. phase 1	1.03(0.80,1.33)	0.81
Phase 3 vs. phase 1	0.90(0.66,1.23)	0.50
Age (1 year older)	0.96(0.95,0.98)	<0.0001
Main Carer – Nursing	2.36(1.38,4.05)	0.0018
Main Carer – LA/Voluntary	2.85(1.64,4.96)	0.0002

Table 7 - Current Criminal Procedures Act - Odds Ratios (95% CI)

Contrast	Odds Ratio (95% CI)	P-value
Phase 2 vs. phase 1	0.69(0.44,1.06)	0.090
Phase 3 vs. phase 1	0.89(0.58,1.36)	0.58
Male	16(2,121)	0.0066
Registered with GP	4.15(1.65,10.4)	0.0024
Age (1 year older)	0.92(0.87,0.96)	0.0006
Detention under MHA	3.71(1.52,9.12)	0.0041

Detention in last 12 months

There was a large reduction in the proportion detained under the Mental Health Act in the last 12 months, from about 20% at baseline to 12% at both phase 2 and phase 3 (see Figure 14). These reductions were statistically significant, and equated to a reduction in the odds of 39% at phase 2 and 31% at phase 3. For every 1 year older, the odds reduced by 3%, and having attempted suicide in the previous 12 months increased the odds by 244%, while being a user of any additional service increased the odds by 71% (Table 8).

Figure 14 - Detained Under MHA in last 12 months

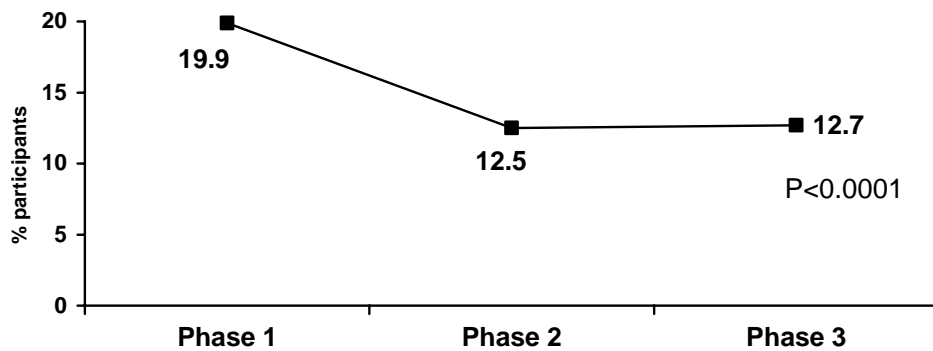


Table 8 - Detained under MHA in last 12 months - Odds Ratios (95% CI)

<u>Contrast</u>	<u>Odds Ratio (95% CI)</u>	<u>P-value</u>
Phase 2 vs. phase 1	0.61(0.49,0.76)	<0.0001
Phase 3 vs. phase 1	0.69(0.54,0.89)	0.0038
Age (1 year older)	0.97(0.96,0.99)	<0.0001
Suicide Attempt	3.44(1.93,6.12)	<0.0001
Additional Services Y/N	1.71(1.28,2.29)	<0.0001

Medication

Antipsychotic medication: regular vs discretionary

Just about all participants (>99%) were on regular antipsychotic medication at all years. No statistical model is therefore reported on the influence of time or covariates on this outcome.

For discretionary medication, there was a non-significant decrease from about 20% to just under 17% over the 2 phases of follow up (see Figure 15). Any episode of self harm in the previous 12 months approximately doubled the odds of using an additional discretionary antipsychotic (Table 9).

Figure 15 - Antipsychotic Medication: regular vs. discretionary

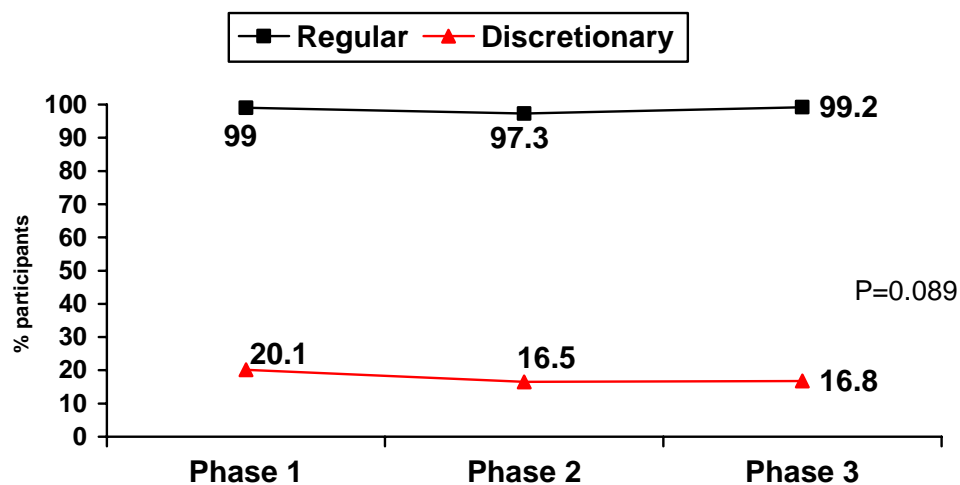


Table 9 – Discretionary Antipsychotic Medication - Odds Ratios (95% CI)

<u>Contrast</u>	<u>Odds Ratio (95% CI)</u>	<u>P-value</u>
Phase 2 vs. phase 1	0.93(0.74,1.16)	0.50
Phase 3 vs. phase 1	0.95(0.75,1.21)	0.68
Self Harm	1.82(1.22,2.73)	0.0036

Antipsychotic medication: typical vs atypical

There was a large decrease in the use of typical antipsychotic medication, from 55% to 45% over the 2 phases (Figure 16). This equated to a reduction of odds of about one third by year 2 (33%). Age was also a positive predictor - with an increase in odds of about 3% for every year older, whilst being diagnosed more than 5 years ago more than doubled the odds. There was also an approximate doubling of the odds for both being detained under the Mental Health Act or having at least one episode of self harm (both at any time over the previous 12 months). There was a corresponding increase in atypical medication, from about 65% to just over 71%, giving an increase in odds of about one third (33%) by phase 3. Here, the direction of age and being diagnosed more than 5 years ago was reversed, as one would expect, given the results for the typicals above - now the older a participant, the less likely they were to have atypical medication (reduction in odds of 3% for every year older), and the odds reduced by about one third (31%) if they had been diagnosed more than 5 years ago (Table 11).

Figure 16 - Antipsychotic Medication: Typical vs. Atypical

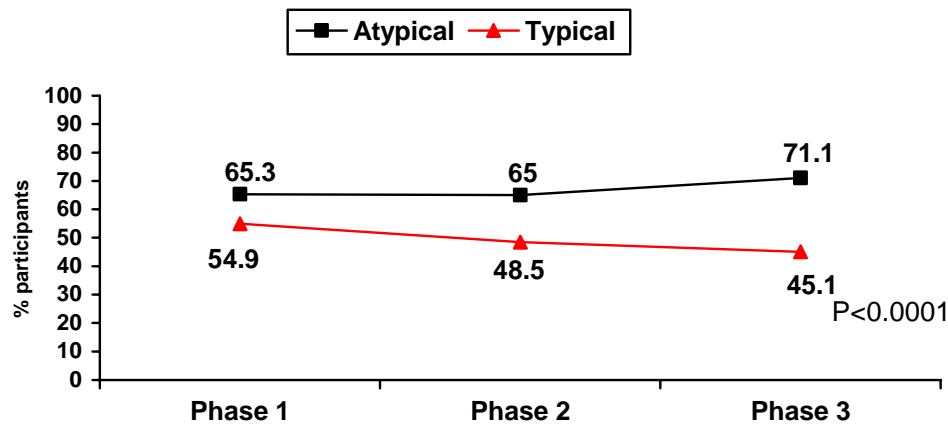


Table 10 - Typical Medication - Odds Ratios (95% CI)

<u>Contrast</u>	<u>Odds Ratio (95% CI)</u>	<u>P-value</u>
Phase 2 vs. phase 1	0.81(0.71,0.92)	0.0009
Phase 3 vs. phase 1	0.67(0.58,0.77)	<0.0001
Age (1 year older)	1.03(1.02,1.04)	<0.0001
Diagnosed > 5 years	2.18(1.61,2.96)	<0.0001
Detained MHA <12m	1.87(1.43,2.44)	<0.0001
Self Harm	1.77(1.25,2.51)	0.0013

Table 11 - Atypical Medication - Odds Ratios (95% CI)

<u>Contrast</u>	<u>Odds Ratio (95% CI)</u>	<u>P-value</u>
Phase 2 vs. phase 1	0.98(0.86,1.11)	0.71
Phase 3 vs. phase 1	1.33(1.14,1.54)	0.0002
Age (1 year older)	0.97(0.96,0.98)	<0.0001
Diagnosed > 5 years	0.69(0.49,0.97)	0.033

Regular antipsychotic medication: oral vs depot

There were no significant trends over time in the use of either oral or depot medication (Figure 17). Older subjects were less likely to take oral medications (reduction in odds of 2% for each year), whilst they were correspondingly more likely to take the depot medication (an increase in odds of 2% per year) (Table 13). In addition, for the depot medication, being detained under the MHA and being diagnosed more than 5 years ago both increased the odds by approximately 50% (Table 13).

Figure 17 – Regular Antipsychotic Medication: Oral vs. Depot

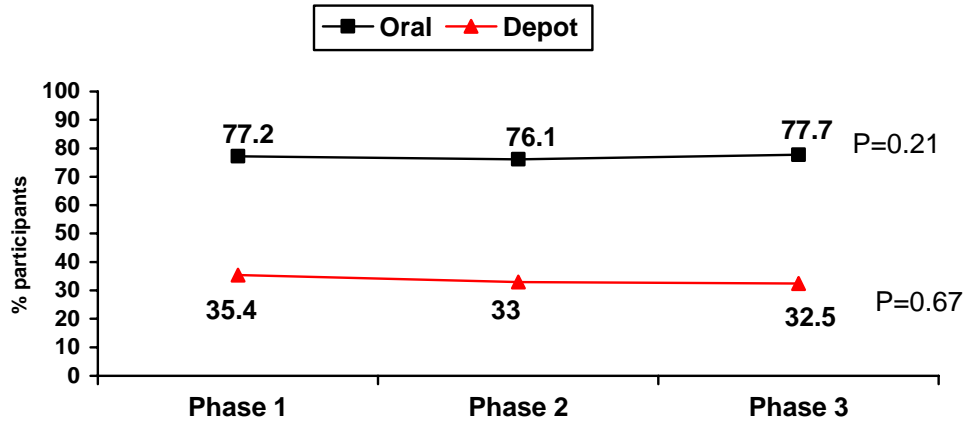


Table 12 - Oral Medication - Odds Ratios (95% CI)

<u>Contrast</u>	<u>Odds Ratio (95% CI)</u>	<u>P-value</u>
Phase 2 vs. phase 1	0.92(0.80,1.05)	0.20
Phase 3 vs. phase 1	1.02(0.88,1.18)	0.80
Age (1 year older)	0.98(0.97,0.99)	0.0006

Table 13 - Depot Medication - Odds Ratios (95% CI)

<u>Contrast</u>	<u>Odds Ratio (95% CI)</u>	<u>P-value</u>
Phase 2 vs. phase 1	0.97(0.88,1.07)	0.53
Phase 3 vs. phase 1	0.92(0.82,1.03)	0.15
Age (1 year older)	1.02(1.01,1.03)	0.0003
Diagnosed > 5 years	1.61(1.13,2.30)	0.0081
Detained MHA <12m	1.40(1.12,1.74)	0.0029

Clozapine

Clozapine use increased from about 23% to about 29% over the duration of the study (Figure 18). As clozapine is licensed for treatment-resistant schizophrenia, and advocated when an individual has not responded to other antipsychotics, an increase in a fixed cohort of participants who are followed over time is not unexpected. The observed increase equated to an increase in the odds of approximately 30%, with older age conferring a 6% reduction per year older in the odds, but being diagnosed more than 5 years ago now giving an increase in odds of 76%, and living with a main carer reducing the odds by about 20% (Table 14).

Figure 18 - Clozapine

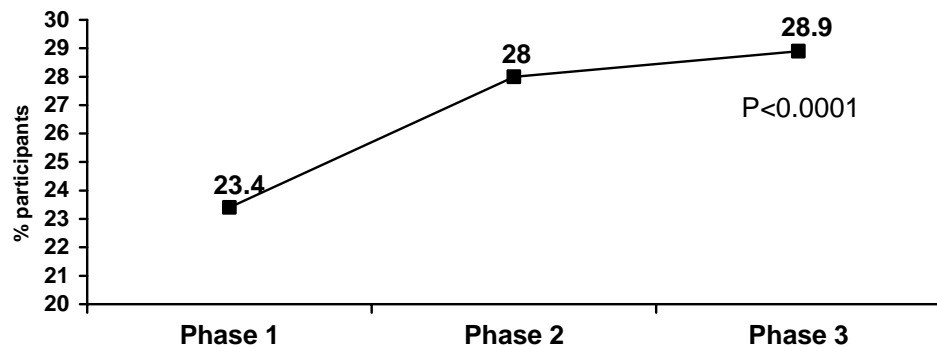


Table 14 - Clozapine - Odds Ratios (95% CI)

<u>Contrast</u>	<u>Odds Ratio (95% CI)</u>	<u>P-value</u>
Phase 2 vs. phase 1	1.25(1.12,1.39)	<0.0001
Phase 3 vs. phase 1	1.30(1.15,1.46)	<0.0001
Age (1 year older)	0.94(0.93,0.95)	<0.0001
Diagnosis >5 yrs	1.76(1.20,2.59)	0.0038
Lives with Main Carer	0.80(0.66,0.97)	0.022

Antidepressant and Anticholinergic Medication

As Figure 19 shows, antidepressant use has significantly increased, while the use of anticholinergic medication for movement disorders has significantly decreased. Advancing age, being diagnosed more than five years ago and having been detained under the MHA in the previous 12 months, all increased the chances of anticholinergic use (Table 15). Increased antidepressant use was associated with a history of self harm or detention under the MHA in the previous 12 months and use of additional support services (Table 16).

Figure 19 – Antidepressant and Anticholinergic Medication

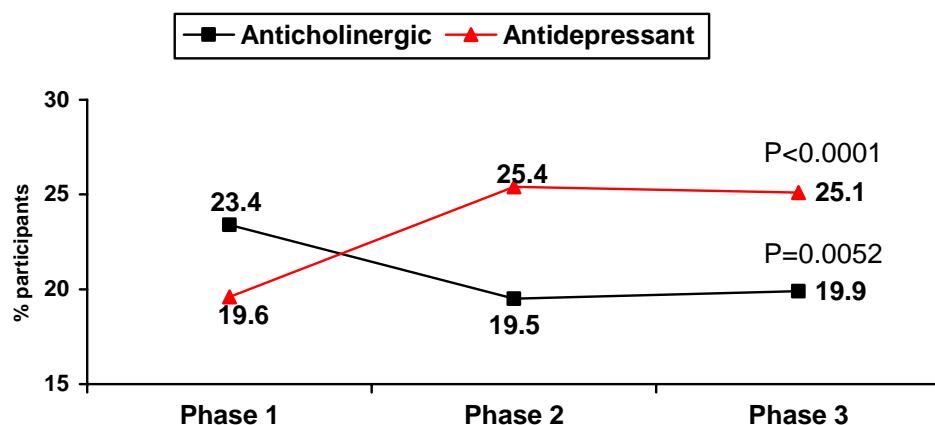


Table 15 - Anticholinergics

<u>Contrast</u>	<u>Odds Ratio (95% CI)</u>	<u>P-value</u>
Phase 2 vs. phase 1	0.82(0.69,0.97)	0.022
Phase 3 vs. phase 1	0.80(0.66,0.97)	0.025
Age (1 year older)	1.02(1.00,1.03)	0.014
Diagnosed >5 years	1.72(1.16,2.56)	0.0071
Detention <12m	1.50(1.14,1.97)	0.0037

Table 16 - Antidepressants

<u>Contrast</u>	<u>Odds Ratio (95% CI)</u>	<u>P-value</u>
Phase 2 vs. phase 1	1.42(1.21,1.67)	<0.0001
Phase 3 vs. phase 1	1.40(1.16,1.69)	0.0006
Male	0.48(0.37,0.62)	<0.0001
Detention <12m	0.64(0.48,0.86)	0.0031
Self Harmed <12m	1.77(1.21,2.58)	0.0031
Additional Services (Y/N)	1.10(1.02,1.18)	0.018

Mood stabilisers and Anxiolytics

There was no significant change in the use of mood stabilisers or anxiolytics across the duration of the project (Figure 20). As Table 17 shows diagnosis more than 5 years ago and use of additional support services was associated with being on a mood stabilizer, while being diagnosed more than 5 years ago was associated with anxiolytic use (Table 18).

Figure 20 - Mood stabilisers / Anxiolytics

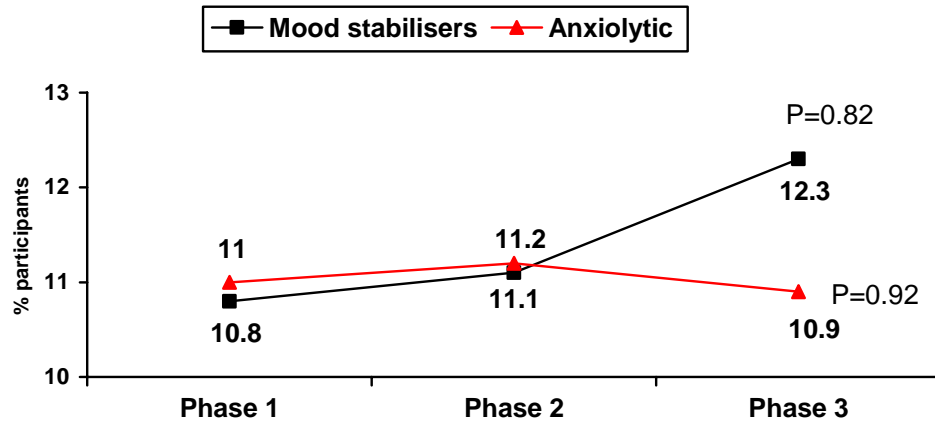


Table 17 – Mood Stabilisers

<u>Contrast</u>	<u>Odds Ratio (95% CI)</u>	<u>P-value</u>
Phase 2 vs. phase 1	0.96(0.78,1.18)	0.68
Phase 3 vs. phase 1	1.03(0.83,1.28)	0.79
Male	0.58(0.40,0.85)	0.0047
Diagnosed >5 years	1.94(1.17,3.22)	0.011
Additional Services (Y/N)	1.14(1.02,1.27)	0.019

Table 18 - Anxiolytics

<u>Contrast</u>	<u>Odds Ratio (95% CI)</u>	<u>P-value</u>
Phase 2 vs. phase 1	1.11(0.89,1.39)	0.35
Phase 3 vs. phase 1	1.06(0.84,1.34)	0.62
Age (1 year older)	0.98(0.97,1.00)	0.017
Male	0.58(0.40,0.83)	0.0031
Diagnosed >5 years	1.64(1.00,2.68)	0.048

Substance misuse

Despite 13% of participants at phase 1 having comorbid substance misuse, alcohol and drug services were used by only a small proportion of participants (5.4%) (see Figure 21). It can also be seen that there has been little change in the use of alcohol services, and a slight increase in the use of drug services by the cohort (Figure 21). The use of drug services was associated with being older and receiving additional support services (Table 19) while the use of alcohol services was associated with a suicide attempt in the last 12 months and the receipt of additional support services (Table 20).

Figure 21 – Use of Drugs and Alcohol problem services

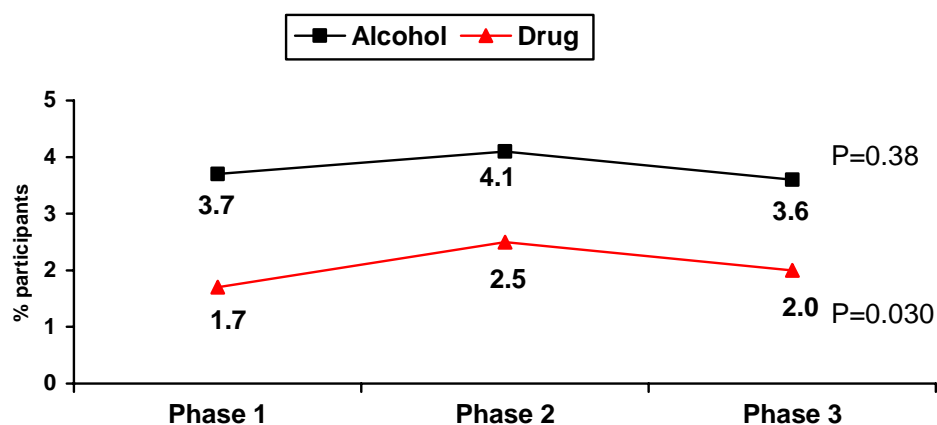


Table 19 – Drug Services

<u>Contrast</u>	<u>Odds Ratio (95% CI)</u>	<u>P-value</u>
Phase 2 vs. phase 1	1.83(1.22,2.76)	0.0037
Phase 3 vs. phase 1	1.44(0.81,2.58)	0.22
Age (1 year older)	0.92(0.89,0.96)	<0.0001
Additional Services (Y/N)	2.06(1.68,2.53)	<0.0001

Table 20 – Alcohol Services

<u>Contrast</u>	<u>Odds Ratio (95% CI)</u>	<u>P-value</u>
Phase 2 vs. phase 1	1.39(1.02,1.91)	0.039
Phase 3 vs. phase 1	1.24(0.81,1.89)	0.32
Suicidal attempt <12m	2.88(1.52,5.47)	0.0012
Additional Services (Y/N)	2.37(2.00,2.80)	<0.0001

Social Work

There was a significant decrease in the proportion of participants accessing social work services across the three phases (see Figure 22). As shown in Table 21, the chances of receiving social work services was increased by living alone, having been detained in the last 12 months and being in receipt of additional support services; however, being male appeared to decrease slightly the chance of receiving social work input.

Figure 22 – Social Work

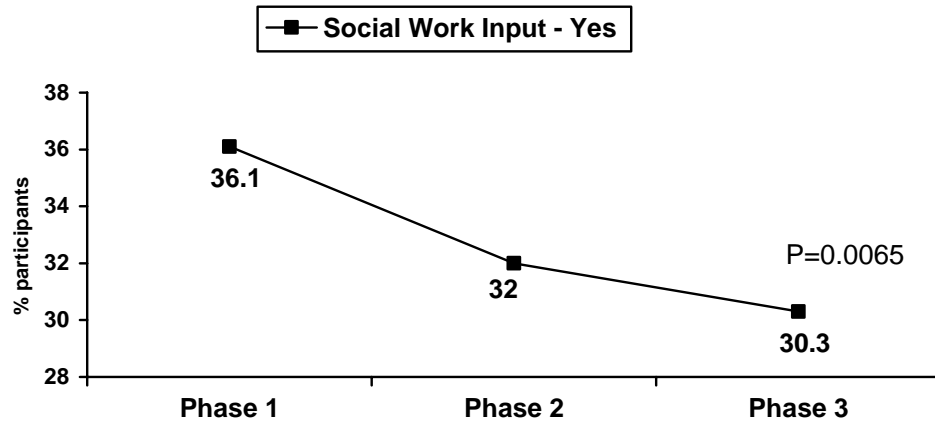


Table 21 – Social Work

<u>Contrast</u>	<u>Odds Ratio (95% CI)</u>	<u>P-value</u>
Phase 2 vs. phase 1	0.94(0.78,1.13)	0.50
Phase 3 vs. phase 1	0.84(0.68,1.04)	0.11
Male	0.73(0.56,0.96)	0.024
Lives Alone	1.80(1.41,2.30)	<0.0001
Detention <12m	1.84(1.37,2.48)	<0.0001
Additional Services (Y/N)	2.90(2.61,3.22)	<0.0001

Avon

An increase in the Avon score represents improvement, as self rated by the participant. Total Avon scores increased significantly across the 3 phases (Figure 23) and this was true for all five sections of Avon (Figure 24). An increased chance of an improved Total Avon Score was associated with being male and the use of Clozapine. Self harm and the use of discretionary antipsychotic medication was associated with a reduced chance of improved total Avon (Table 15).

Figure 23 - Avon: mean of component scores (expressed as %)

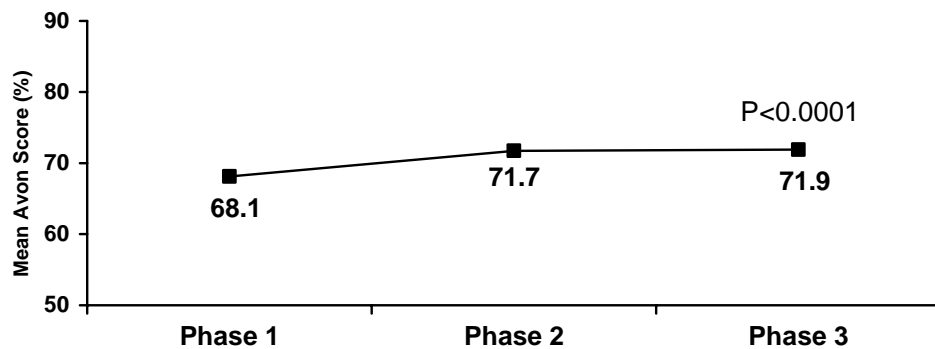
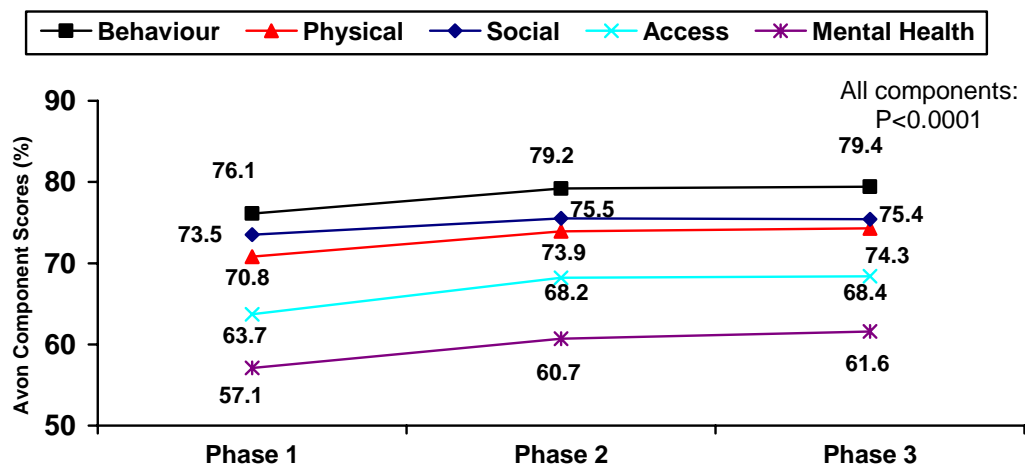


Table 22 - Total Avon - Mean change (95% CI)

Contrast	Mean Change (95% CI)	P-value
Phase 2	2.87(2.14,3.62)	<math>< 0.0001</math>
Phase 3	3.40(2.47,4.32)	<math>< 0.0001</math>
Gender male	2.33(0.72,3.94)	0.0047
Self Harm	-5.56(-7.62,-3.50)	<math>< 0.0001</math>
Clozapine	2.18(0.89,3.47)	0.0009
Discretionary medication	-1.76(-3.04,-0.47)	0.0074

Figure 24 – Avon: mean individual component scores (%)



HoNOS

A reduction in HoNOS scores represents improvement. Across the duration of SSOS, total HoNOS scores and Behavioural and Symptom sub-scores remained unchanged, while Impairment sub-scores significantly increased (representing increased impairment) and Social sub-scores significantly decreased (representing improved social functioning) (see Figures 25 and 26).

Figure 25 – HoNOS: mean total scores (expressed as %)

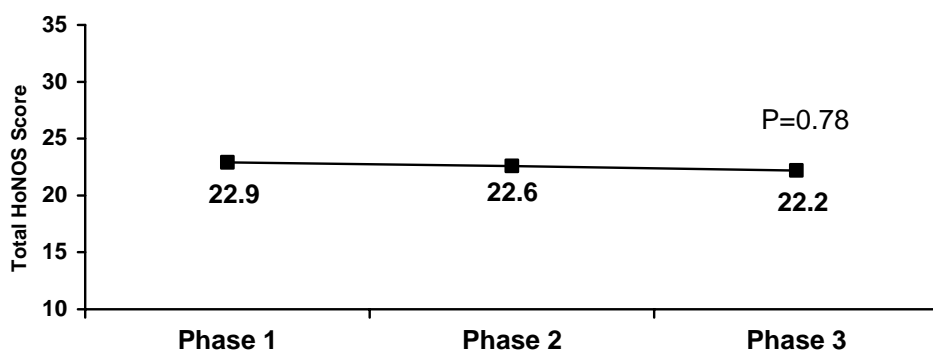
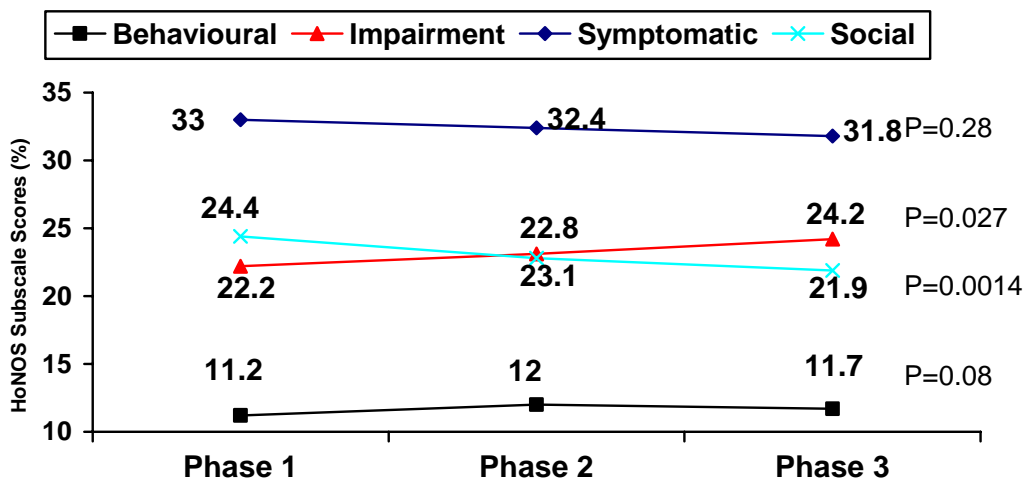


Table 23 - Total HoNOS - Mean change (95% CI)

Contrast	Mean Change (95% CI)	P-value
Phase 2	0.19(-0.55,0.94)	0.61
Phase 3	-0.02(-0.94,0.90)	0.97
Additional Services (per service)	1.34(0.95,1.74)	<0.0001
Lives with Main Carer	1.75(0.62,2.89)	0.0025

Figure 26 – HoNOS: mean individual HoNOS subscores (expressed as %)



5.5 Outcome measures: Regional performance

The observed performance of different NHS organisations with respect to their expected performance for hospitalisation, use of the CPA, total HoNOS, and total Avon scores is described in Figures 27 to 30. For all four areas of outcome most NHS organisations were observed to perform consistently with expected performance based on the other NHS services in Scotland. It can be seen however that a small number of NHS services had higher (worse) HoNOS scores than expected compared with the rest of Scotland; a small number had higher (better) Avon scores; a small number had more hospitalisation and used CPA more often than the rest of Scotland. For comparison purposes each NHS organisation is identified by a code in order to allow comparison for each NHS organisation to be made across all four outcome areas. For the first plot (Figure 27), the regions are identified A through to N, from left to right. These same labels are then used consistently throughout the remaining three Figures 28-30.

Figure 27 - Psychiatric Hospitalisation Regional Performance

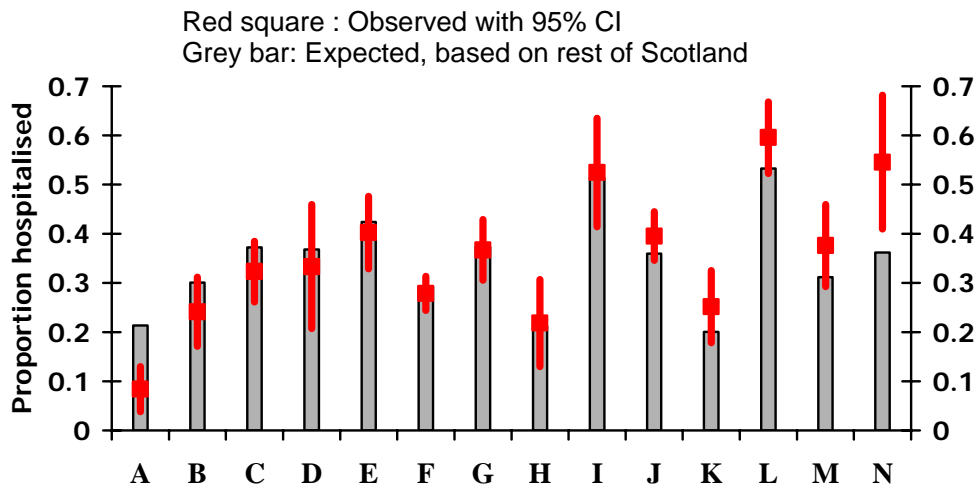


Figure 28 - Care Programme Approach (CPA) Regional Performance

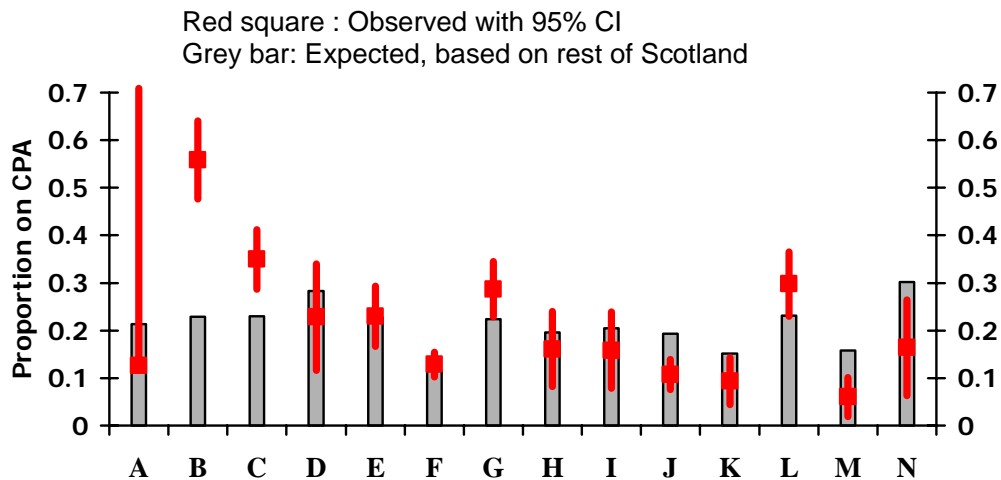


Figure 29 - Total HoNOS Regional Performance

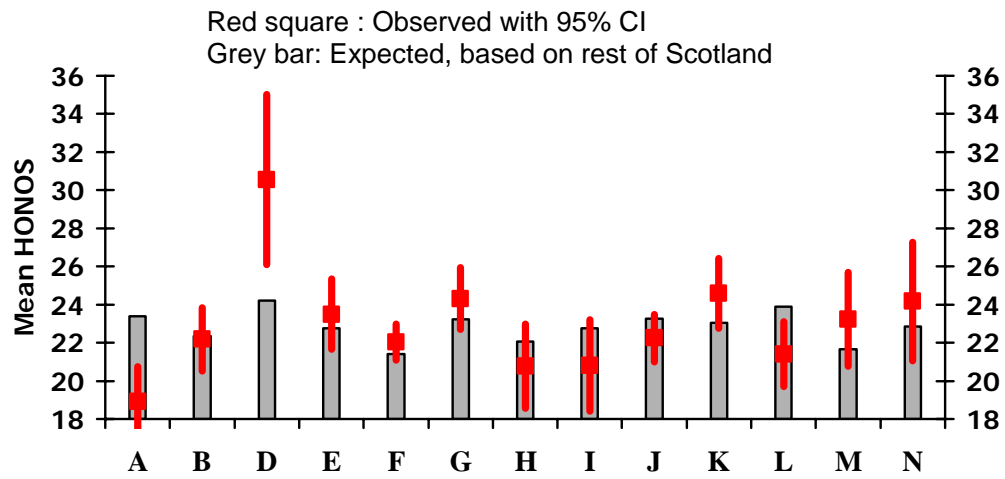
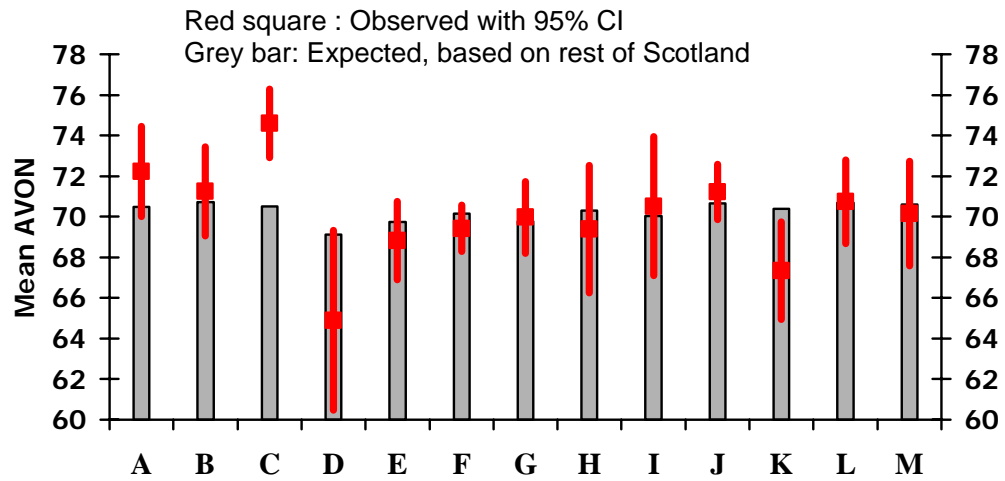


Figure 30 - Total Avon Regional Performance



NB – Organisation **C** is omitted from Figure 29 as they did not use HoNOS
Organisation **N** is omitted from Figure 30 as they did not use AVON.

5.6 *Clinical Standards for Schizophrenia*

Figure 31 shows the proportion of the total number of essential criteria of the Standards met by each NHS organisation in Scotland (mean of 21%; 95% Confidence Interval 16% - 26%) for all NHS organisations. Figure 32 shows the mean proportion (with confidence intervals) of NHS organisations meeting essential criteria of each of the 11 standards. With the exception of standard 1 (Information on Populations and Individuals) where no NHS organisation achieved implementation, there was fairly uniform low implementation of standards across NHS organisations, with none reaching more than 50%.

Figure 31 – Proportion of Standards met by each Health Board area

*the State Hospital is included in this chart as it participated in the assessment of compliance with the Standards.

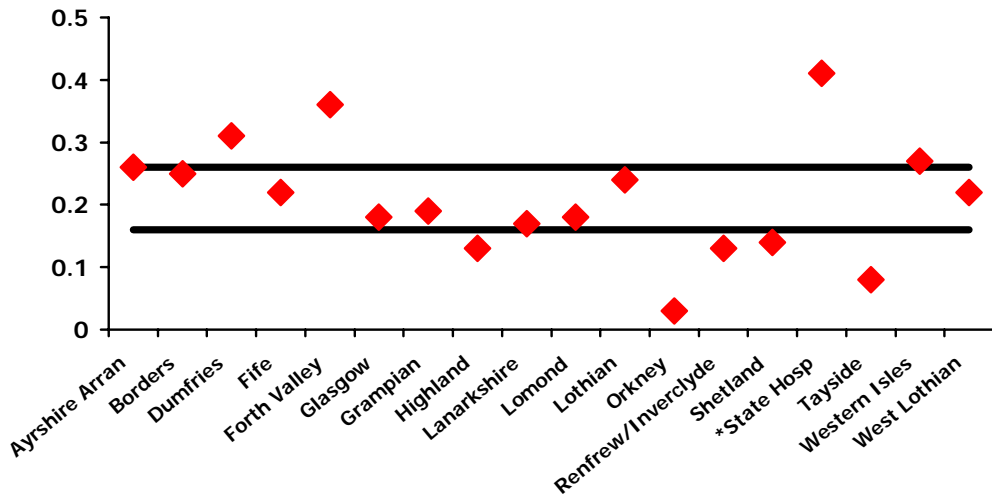
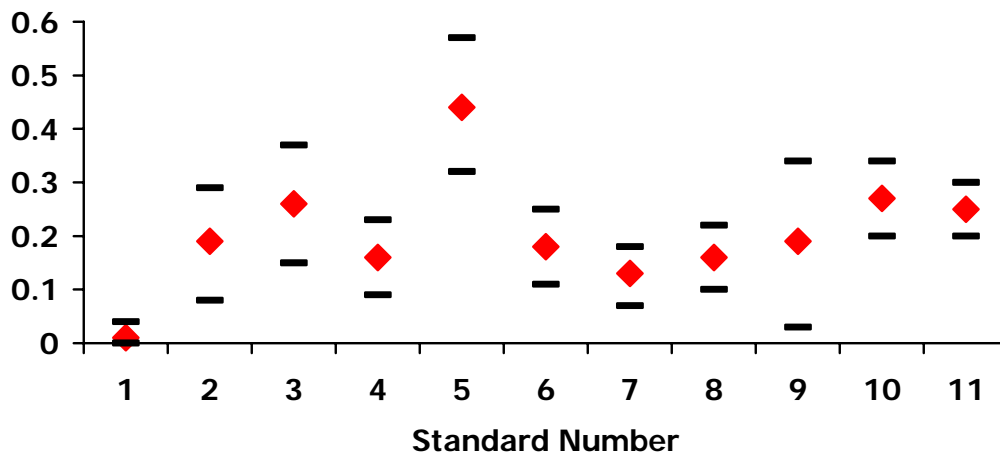


Figure 32 – Proportion of NHS Organisations meeting each Standard



6. Discussion

6.1 Establishing the routine collection of user-centred and pragmatic clinical outcome data

SSOS successfully established the routine collection of outcomes data on an annual basis over three years across nearly every NHS Organisation in Scotland including urban, island and rural communities. The only exception was the State Hospital where clinicians felt that service provision was of a specialised nature, and decided not to participate. The project took place in routine clinical settings encompassing different types of service provision across hospital and community settings. Moreover, areas with differing levels of deprivation were included.

The core outcome measures (HoNOS and Avon), recommended by SSOS to keyworkers participating in the study, appeared acceptable to most keyworkers (89% of 592 trained) (see Hunter et al 2004 for Avon vs. HoNOS acceptability). In some services where the use of CANSAS or FACE was established, some keyworkers continued to use these specific tools in conjunction with the core tools (8% Avon and FACE; 2% Avon and CANSAS; 1% HoNOS and CANSAS).

The benefits of a user-centred approach such as Avon or FACE, as opposed to measures rated by clinicians such as HoNOS or CANSAS, include the potential for better therapeutic alliances with patients, new information on patients for keyworkers, and possibly improved compliance with treatment plans. This type of approach is in keeping with evidence that demonstrates the benefits of involving people in their care management.

Problems encountered in establishing the routine collection of outcomes data by SSOS include the following:

- The relatively high turnover of keyworkers not only resulted in a change of keyworker for participants, but new keyworkers required training in the use of outcome measures in order to ensure inter-rater reliability.
- Although SSOS resulted in a large number of keyworkers being trained in the use of outcome measures across Scotland, the training requirements of the study were underestimated at the outset. The importance of training is crucial to the successful establishment of outcome measures in routine practice.

6.2 Assessing the feasibility of routinely collecting outcome data

Evidence from SSOS (e.g. participant numbers, training workshops, data collection, staff trained, etc) shows clearly that even on a relatively small budget it is feasible to routinely collect outcome data across the Scottish mental health service. SSOS focused on schizophrenia, one of the more complex areas of mental health care. It is a reasonable proposition that if outcome data of this kind can be collected in schizophrenia, it should be achievable in conditions where service user understanding and cooperation is likely to be better, e.g. Bipolar Disorder, Depression, or Anxiety.

Previous efforts to establish routine mental health outcome collection have been largely *unsuccessful* in the NHS; some of the reasons for this include:

- Lack of understanding and appreciation by service managers of the effort and investment needed
- Top-down initiatives with insufficient 'ownership' from clinicians
- Unidisciplinary approaches rather than multidisciplinary involvement
- Outcomes proposed often too 'research' oriented in style for clinicians (too long, complex, of questionable relevance, concerns about their impact on routine

- o clinical work, and administration by time-limited research assistants)
- o Lots of short term projects, less longer term investment
- o Lack of IT and administrative support for staff
- o Outcome measures often seen as not clinically relevant, and more germane to service management goals

SSOS has demonstrated that the methodology used in this national demonstration project has enabled staff to better understand the use of outcome measures and be involved in a quality improvement process for patients. Other investigators have recognised that there is reluctance in the UK for psychiatrists to use outcome measures (Gilbody et al 2002). In the design of SSOS, a deliberate decision was taken to recruit mental health nurses as keyworker participants. This seemed appropriate given their important role in the care of people with schizophrenia and their close working relationship with psychiatrists. In SSOS 83% of keyworkers were mental health nurses. SSOS has also shown that patients, with a condition as severe as schizophrenia, can be involved in the process. The key principles underpinning the methodology used in SSOS have been:

- o Understanding the study aims - it was imperative that keyworker clinicians understood the key aims of the study and why it was being undertaken
- o Encouraging a culture of quality improvement with a multidisciplinary team approach to the care process
- o Effectiveness - clinicians were asked to undertake processes that would potentially make a difference to care planning
- o Relevance - only clinically relevant information was collected
- o Achievable - data collection had to be do-able within routine daily practice without too much disruption
- o Stakeholder Involvement - it was important that both staff and participants felt involved and valued within the process, with participants (service-users) having the opportunity to express their views on their needs. Avon was readily accepted as a service user measure with utility for mental health teams and also as a way of giving service user's a means of contributing to their care plan.
- o Education - the process was rigorously underpinned by education and training
- o Benchmarking - clinicians were encouraged to understand the importance of benchmarking between local, regional and national practice
- o Dissemination - regional and national meetings were a key focus for information sharing and networking

The elements of this way of working include incorporating service user centred needs assessments within a minimum data set and has been underpinned by education and training. The process was driven forward and sustained using a central support function. These ways of working are generalisable throughout mental health services and could form part of an integrated care pathway process to ensure continuous quality improvement.

It was important to work in partnership with key organisations that are able to encourage and facilitate change e.g. Scottish Executive Health Department, NHS QIS, local NHS Boards, Royal College of Psychiatrists, SAMH, etc. and also to work with key service managers and other clinical effectiveness staff (the NAG membership). These key managers within the NHS have influence up and down the organisation; crucially they have influence with health professionals especially nurses and doctors who are two of the key groups of staff needed to successfully introduce outcome measures within pathways of care.

SSOS benefited from having a central national office that became a source of expertise on outcomes and a reference point for advice and training. Training was

underestimated by SSOS initially and SSOS has shown that there is a considerable demand for training. In SSOS the most cost effective model for training was to provide training for some individuals to become trainers in their locality.

Data return systems need to be efficient; when SSOS started we considered different ways of transferring data to the study centre and concluded that postal transfer was probably the simplest and most readily available method throughout the country. The use of email for returning data was considered, but under the terms of the Data Protection Act, confidentiality and security of electronic transmission of data could not be guaranteed. Also, at the start of the study only 25% of keyworkers had email access at work, while at the conclusion of the project this increased to around 75%.

It was important for SSOS to be able to sustain these developments over the lifetime of the project. On a modest budget the approach taken by SSOS was able to sustain the efforts of clinicians to collect outcomes data over nearly four years. Other elements that helped to sustain and embed the use of outcomes included: an agreed and reasonably simple data sheet, regular steering group meetings (especially of NAG members with local influence), adequate resources to host meetings, newsletters, a web site for information and support, regular feedback to clinicians, central data handling, and a national annual meeting of outcome users. The three annual meetings helped enormously to build a common sense of purpose and encourage effective networking.

Novel elements in future could make better use of IT systems, particularly for the collection of outcome information, e.g. waiting areas might accommodate 'touch screen' PC based needs or outcome questionnaires for service users with immediate feedback to the service user and the provision of summarised data for their clinician. Such systems have been used in cancer services in Edinburgh and appear popular and an efficient use of waiting time.

6.3 Describing the pattern of outcomes for schizophrenia across areas of Scotland

An important issue was whether the SSOS sample was representative of people in Scotland with schizophrenia who were receiving services. The sample represents approximately 10% of people with schizophrenia in contact with NHS services in Scotland and is one of the largest cohorts anywhere in the world followed up in this way. Schizophrenia, for almost all those diagnosed with the condition, is a life-long condition of relapsing and remitting course. By these criteria the SSOS cohort represents at least a significant proportion of those with schizophrenia in Scotland in contact with NHS services.

Participants to SSOS were recruited from the wide range of NHS services for schizophrenia. To participate, patients required an ICD-10 diagnosis of F20 – F29, i.e. schizophrenia or a related disorder, and had to be aware of this diagnosis; patients who were not aware of their diagnosis were not approached for consent. On some occasions however, the issue of diagnosis led to discussion about diagnosis with the Responsible Medical Officer (RMO), which was reported as helpful. In a very few cases potential participants were not included on account of being too unwell; participants were included from acute settings if they were judged to be able to give informed consent. Some participants may have been dissuaded from taking part by the Ethics Committee requirement for signed consent which in a condition such as schizophrenia can sometimes be problematic. The Ethics review of clinical effectiveness studies such as SSOS may benefit from a different approach to that taken with clinical trials of interventions.

Examination of these issues across the regions of Scotland did not reveal evidence that any one of these factors was operating more in one area than in another. In each area, factors such as being unable to give informed consent, being too unwell, reluctance by keyworkers to recruit because of diagnostic or work load issues, were operating equally and therefore the sample recruited in each area, on these considerations, was thought to be reasonably comparable. However, the relative proportions of participants attending different types of service along the care pathway for schizophrenia (e.g. rehabilitation or acute admission) did vary across the country, which limits considerably the usefulness of comparing the performance of different services. For this reason, we chose in our analyses to compare participating NHS organisations with the rest of the SSOS cohort, rather than make comparisons between individual organisations (see Section 6.4).

It is important to emphasise that SSOS, as a *clinical effectiveness* study rather than an *efficacy* study, relied on naturalistic, observational methodology that utilised entry criteria for participants from the 'real world' of NHS services. All individuals recruited had an ICD-10 diagnosis of schizophrenia and schizophrenia-related disorders (as ascertained by their consultant psychiatrist) and were receiving services from NHS Scotland. As such the SSOS sample is more representative of people with schizophrenia receiving NHS services than, for example, the carefully selected participants recruited to drug or other efficacy studies. In this respect the findings from SSOS should be generalisable to the NHS. In a study of the scale and type of SSOS, aimed at improving clinical effectiveness, the design employed utilised patients' keyworkers for data collection, rather than specially trained research assistants. This seemed a necessary prerequisite if SSOS was to inform the question of feasibility within services for schizophrenia.

All keyworkers participating in SSOS were trained professionals who underwent a standard training package with refresher sessions as necessary. SSOS placed a considerable emphasis on the importance of training for reliability and validity. The experience of SSOS, and other centres such as those in Australia (see Trauer et al, 2002) and Canada (S Kisely, SSOS National Conference 2005), is that the successful implementation of outcome measures into clinical services requires an effective and adequately resourced training infrastructure. Using appropriate training, acceptable levels of inter-rater reliability can be achieved in a study of this size and type. This was examined in detail in the Scottish 700 Study, where clinicians were similarly trained to use HoNOS and Avon (Hunter et al. 2004). In practice much of the focus for the use of outcomes will be at a team level where issues of inter-rater reliability can be addressed, again by training systems that ensure that adequate standards are maintained.

Trends over time for pragmatic outcomes (hospitalisation, use of Care Programme Approach, suicidal and self-harm attempts, and use of mental health legislation), indicated improvement over the duration of the study. The improvements in pragmatic outcomes were consistent with the self-reports from Avon, while HoNOS trends were constant over the study period. This suggests that keyworkers were assessing participants to be stable, rather than improving or becoming more impaired. This apparent disparity between HoNOS and Avon emphasises the importance of including a service user centred measure such as Avon. Added value is achieved by the care team incorporating service users' views, as reflected in Avon, in care planning (Markovitz 1999).

There was little change in the proportion of the cohort diagnosed with comorbid substance misuse (including alcohol); this was 13% at baseline and 10% in phases 1 and 2. A further 20% of the cohort were also considered to have significant substance

misuse problems. However, despite approximately 30% of participants being considered to have substance misuse problems at syndrome or subsyndromic level, only a relatively small number of participants (approximately 6%) were receiving drug or alcohol services across the course of SSOS. Given the well recognised adverse effects of substance misuse on health and social outcomes in schizophrenia these data give cause for concern. Furthermore, relatively small numbers of participants were receiving psychological or other treatments. There was also a trend towards a significant decrease in the proportion of participants receiving social work support across the three phases.

A trend towards polypharmacy was noted in SSOS with 70% of the cohort taking 2 or more types of medication. SSOS studied a multi-episode cohort, typical of most people with schizophrenia; the use of older types of antipsychotic medication (first generation or typical antipsychotics) declined, while there was an increase in the use of newer second generation (atypical) medication. There was also a trend for less discretionary antipsychotic medication to be used by participants. Although no trend was detected with respect to the use of depot antipsychotic medication, a significant increase in the use of Clozapine occurred, probably reflecting the numbers of participants who have not received adequate symptomatic improvement from other types of antipsychotic medication. During the course of SSOS, antidepressant use increased although no significant increase in mood stabilizers or anxiolytics was noted. The reduction in anticholinergic medication may reflect increased use of atypical antipsychotics which have less propensity to cause movement disorders.

6.4 Assessing the impact of the introduction of the Clinical Standards for Schizophrenia

These changes in outcomes and interventions occurred during the time period when the Standards were introduced, but it is not possible within the current study design to conclude any causal association. It should also be appreciated that as the Standards were introduced in every Health Board area, there was no opportunity for a controlled study. From data published by NHS QIS (National Overview 2004) it is clear that only around 21% of the essential criteria for the Standards was met on average by each health board area. Furthermore only about 20% of essential criteria for each standard was met. These results show that the *implementation* of the Standards was at best only partial. It should also be borne in mind that over the period of the study there have been significant changes in mental health service provision across Scotland. These include the development of community mental health teams (CMHTs), more specialist services, the introduction of the National Institute for Clinical Excellence (NICE) and other guidance and a reduction in the number of available acute psychiatric beds. These developments, along with the momentum and halo effect from the Standards initiative may have contributed in a positive way to clinical practice, and to the improvement in outcomes observed in SSOS.

6.5 Describing the resource use associated with routine collection of outcome data.

Clearly, a detailed resource utilisation analysis was outwith the scope of this project. Such an analysis of the SSOS process would require a specific health economic study, and as previously stated (Section 5.11) this is under discussion. The resources utilised in undertaking the current study are described in the methodology (Section 5.12). At the 2nd National SSOS Meeting, a health resources workshop was led by a Health Economist at Glasgow University, where the majority of participating clinicians supported the view that the assessment of needs and outcomes should form an integral part of their work with service users. Furthermore, in a survey of a representative sample of 142 keyworkers who participated in SSOS, 94% indicated that they intended to continue to use outcome measures after the completion of SSOS.

Standard 4 of the schizophrenia Standards recommended that a person's need for care and the outcomes of the care provided should be assessed using validated rating scales that include the service user's perspective (CSBS; Evidence Base, 2001). More recently the Mental Health (Care and Treatment) (Scotland) Act 2003, introduced in 2005, requires that in utilising the legislation, mental health needs are systematically assessed. The introduction of Integrated Care Pathways (NHS QIS Strategic Work Programme, 2005), will allow needs and outcomes to be assessed regularly within the normal care offered to patients. It is therefore reasonable to expect that the assessment of needs and outcomes within these changes in practice may not necessarily require additional resources for implementation.

7. Conclusions and Recommendations

- 1) SSOS has clearly demonstrated over a three year period that in a representative sample of patients with schizophrenia attending the NHS in Scotland, it is feasible to routinely collect mental health outcomes data. The project has demonstrated also that it is feasible to incorporate service user assessments of need into routine practice.

Recommendation

Outcome measures should be incorporated into routine clinical practice across mental health specialties. Assessments should as a minimum, include a clinician rated measure and a service user led assessment of need.

- 2) Evidence from SSOS has demonstrated that there are a range of outcome measures in use across Scotland. During the course of SSOS use of these tools significantly increased. There appears to be more widespread use of HoNOS and Avon.
- 3) Implementation of outcome measures cannot await the introduction of the 'ideal outcome measure', if indeed such a measure is possible. There is however a need to identify a default menu of outcome measures that provide information across the key domains of distinct populations.

Recommendation

NHS organisations should adopt and promote the use of one or more assessment measures from the following menu, ensuring that one is clinician rated and the other a service user led assessment of need:

- Health of the Nation Outcome Scale (HoNOS)
- Avon Mental Health Measure (Avon)
- FACE
- Camberwell Assessment of Need

The use of these core measures would not preclude the use of other specific rating scales to be used as required.

- 4) The use of Avon has facilitated the involvement of service users in their care, and provided valuable information for clinical teams. However, Avon would benefit from updating and being reformatted to improve its ease of use.

Recommendation

The content of the Avon Mental Health Measure should be revised and delivered in a more user-friendly format. The participants in SSOS with experience of Avon, should be involved in this process.

- 5) SSOS has shown that it is essential that the introduction and continued implementation of the use of outcome measures is underpinned by effective training.

Recommendation

NHS QIS should give consideration and support to a national training plan as an element of their National Work Plan 2005-2008, involving NHS Education Scotland (NES) in such plans.

- 6) The key to implementing outcome measures within the mental health service is local ownership and development of implementation strategies. Clinicians will only continue to use outcome measures that have relevance and utility for improving patient care.

Recommendation

Local NHS organisations should ensure outcome measures are incorporated into locally developed Integrated Care Pathways (ICPs) for disease management.

Clinicians should be supported with education, training and support in the local implementation and ongoing use of outcome measures.

- 7) Information Systems (IS) and Information Technology (IT) are under utilised in the collection and reporting of mental health outcome measures throughout Scotland. If outcome measures are to become an integral part of clinical practice it is essential that IS/IT systems are used to provide timeous information to clinicians and service users.

Recommendation

The recording and reporting of mental health outcome measures should be incorporated into the IS/IT strategies of local NHS organisations and provision should be made for an integrated system for the collection and reporting of information on outcomes.

- 8) SSOS has provided a national 'snap shot' of services, interventions and outcomes in people with schizophrenia. Although some trends appear positive, there are areas of concern e.g. uptake of treatments other than medication and participation in employment or training.
- 9) Evidence suggests that the Clinical Standards for Schizophrenia have only been partially implemented. In the future Integrated Care Pathways will become established to deliver and evidence the implementation of standards of care.

Recommendation

It will be essential to follow-up the SSOS cohort in future in order to monitor progress and sustainability in services utilised, interventions and outcomes.

Final Recommendation

The findings and recommendations from SSOS should inform discussion at a national symposium, in order that a consensus view of the way forward with implementing outcome measures in Scotland is achieved.

8. Dissemination

8.1 Final Report

Copies of the final report will be circulated to:

- NHS Quality Improvement Scotland
- All participating organisations
- Members of the Project Advisory Group
- Members of the National Advisory Group
- Scottish Association for Mental Health
- National Schizophrenia Fellowship (Scotland)
- Mental Welfare Commission

Executive summaries will be circulated to all participating keyworkers with the offer of a copy of the final report if requested.

An easy read version will be circulated to participants via their keyworker.

8.2 Publicising SSOS

Two national meetings and a national conference have been hosted by SSOS to disseminate findings from the study and act as a means of sharing practice throughout Scotland and enabling keyworkers to network and share examples of practice with a wider audience.

The first of these events was held in June 2003 and was attended by 149 delegates. The programme for this event can be viewed in *appendix 7*. The main aim of this meeting was to disseminate changes to practice which had been directly influenced by SSOS and were beginning to take place within teams. As a result, many of the speakers at this event were keyworkers involved in the study, but who had not presented their work in a conference setting before. SSOS therefore offered Presentation Skills Training to these people, and to fill the course on the day, offered this training to all keyworkers registered with the study at the time. This resulted in the training course being oversubscribed and led to the creation of a 'waiting list'. Further Presentation Skills Training was offered in 2004 to accommodate this list.

The second national meeting was held in October 2004 and was attended by 120 delegates. Once again this event was about disseminating practice and promoting national initiatives such as the new Mental Health Act. To facilitate this, a series of 5 workshops were delivered. The programme from this event is shown in *appendix 8*.

The third event, a national conference, was held in November 2005 and was an open event to delegates from throughout Scotland. This was attended by 121 delegates and once again involved people who had participated in the study describing how SSOS has influenced change to their practice; as well as invited international speakers, who described their ongoing work regarding the implementation of outcome measures in England, Canada and Italy. The programme is shown in *appendix 9*.

Sixty-five awareness sessions regarding the aims of the study were delivered throughout the nineteen participating sites at the beginning of the study.

8.3 Dissemination

Dissemination has included oral and poster presentations:

1. **Hunter R (2002)**
'The Scottish Schizophrenia Outcomes Study (SSOS)'.
Invited paper to the *National Congress of the Scottish Mental Health Research Network*, Crieff. 1st February 2002.
2. **Hunter R and Cameron R (2002)**
Scottish Schizophrenia Clinical Outcomes Study.
Health of the Nation Outcome Scales Users Forum Newsletter, issue 7: 2.
Royal College of Psychiatrists, London.
3. **Hunter R & Cameron R (2003)**
International Workshop on Outcome Measures
College Research Unit, Royal College of Psychiatrists, London 7th July 2003
4. **Cameron R and Hunter R (2004)**
The Scottish Schizophrenia Outcomes Study.
World Journal of Biological Psychiatry 5: S1, 141.
5. **Cameron R and Hunter R (2004)**
The Scottish Schizophrenia Outcomes Study - Phase 1 data.
ICP Congress, Italy. September 2004.
6. **Hunter R (2004)**
The Scottish Schizophrenia Outcomes Study.
NHS Quality Improvement Scotland: Good Practice Event, Carlton Hotel, Edinburgh. 14 June 2004
7. **Hunter, R, Cameron R & Divers C (2004)**
The Scottish Schizophrenia Outcomes Study.
NSF Scotland Newsletter, Summer 2004 edition.
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11. Appendices

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Members of the Project Advisory Group

Prof. Robert Hunter	Consultant Psychiatrist	Project Convenor
Rosie Cameron	Project Coordinator	
Mr Sean Doherty	Mental Health Team Leader	NHS Quality Improvement Scotland
Mrs Sandra Dow	Carer Representative	National Schizophrenia Fellowship (Scotland)
Dr Sheila Gilfillan	Consultant Psychiatrist	NHS Lothian – West Division
Dr Alistair Hay	Consultant Psychiatrist	NHS Highland
Dr Caroline Mitchell	Consultant Psychiatrist	NHS Lanarkshire
*Mr John Norrie	Director	CHaRT, University of Aberdeen
Mr Richard Norris	Director	Scottish Health Council (formerly of SAMH)
*Prof. Dave Peck	Area Clinical Psychologist	(formerly of NHS Highland)
*Dr Ian Pullen	Psychiatric Advisor	Scottish Executive Health Department
Dr Andrew Walker	Health Economist	Robertson Centre for Biostatistics, Glasgow University

Founder member: *Dr Fiona Lang, Clinical Advisor, Clinical Standards Board for Scotland

* Shona Barcus, Chief Executive, SAMH

* indicates additional grant applicants

Members of the National Advisory Group

Prof. Robert Hunter	Consultant Psychiatrist	Project Convenor
Rosie Cameron	Project Coordinator	
Beatrice Cant	Senior Programme Manager, Clinical Effectiveness Coordination Unit	NHS Quality Improvement Scotland
Mark Fleming	Clinical Information Systems Manager	Ayrshire & Arran
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Linda McKechnie	Service Development Manager	Dumfries & Galloway
Avril Herries	CPN	Dumfries & Galloway
Colin Welsh	Team Leader	Fife
Jan Jamieson	Service Development Manager	Forth Valley
Barry Sharp	Team Leader (formerly of Lanarkshire)	Forth Valley
Allan Scott	Clinical Effectiveness Manager	Grampian
Patricia Doig	Clinical Audit Co-ordinator	Greater Glasgow
Michael Perera	Service Development Manager	Highland
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Fiona Corcoran	Clinical Effectiveness Dev. Manager	Lomond & Argyll
Ewen Taylor	CPN	Orkney Health Board
Stephen McGinness	Practice Development Nurse	Argyll and Clyde
Dr Simon Shaw	Consultant Community Psychiatrist	Shetland Health Board
Caroline Paterson	Clinical Effectiveness Facilitator	Tayside
Anne Hutchison	Project Officer	Western Isles Health Board
Jim Watson	CPN	Lothian West Division

Founder member: Andrew Dickson, Head of Nursing MH and LD, Renfrewshire and Inverclyde



Scottish Schizophrenia Outcomes Study



PARTICIPANT INFORMATION SHEET

March 2002

You are being invited to take part in this study. Before you decide whether to take part it is important that you understand why this study is being done and what it will involve. Please take time to read the following information carefully and discuss it with your keyworker or carer. Please ask if there is anything that is not clear, or you would like more information. Take time to decide whether or not you wish to take part. Thank you for taking the time to read this information sheet.

What is the purpose of the study?

The aim of the study is to improve the care of people with a diagnosis of schizophrenia. This study is taking place at a time when National Standards for schizophrenia have been introduced in Scotland. These set out guidelines for mental health services to follow, when providing care and treatment for people with schizophrenia. This study aims to measure the impact of care on outcomes for patients by involving the people who use the mental health services.

Why have I been chosen?

As a patient at a study centre, you have been chosen at random to participate in the study. Approximately 2000 patients from across Scotland will be asked to participate.

Do I have to take part?

It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet to keep along with a copy of a consent form, which you will be asked to sign. If you decide to take part, you are free to withdraw at any time and without giving a reason. If you decide not to take part, or decide to take part and then withdraw, this will not affect the standard of care that you receive.

What will happen to me if I take part?

You will be asked to complete a questionnaire along with your keyworker. You will then be asked to complete the same questionnaire 12 months and 24 months later. You may decline to answer any question, in any of the questionnaires, without giving a reason.

What are the questionnaires about?

The questions you will be asked to complete in the questionnaires will help us to understand your personal needs in many aspects of your life such as: physical, social, behaviour, access and mental health needs. These questionnaires should normally take no more than 30 minutes to complete and your keyworker will be able to help you fill them in.

Will taking part in the study cost me anything?

There will be no cost to you taking part and you will not be asked to visit your keyworker or GP any more often than for your usual treatment plan.

What are the possible benefits of taking part?

The information you provide will of course be shared with your keyworker and there may be benefits to the care you receive as a result of this information. However, this cannot be guaranteed. The information we get from this study may improve the treatment of future patients with schizophrenia.

What if I have concerns about the study?

You will continue to receive your normal care throughout the duration of this study. Your keyworker will be involved throughout the study period and will be able to answer any concerns you have. Alternatively, you may contact Rosie Cameron, who is the Project Co-ordinator, by telephoning 0141 211 3582 to discuss any concerns you may have. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms are available to you.

Will my taking part in this study be kept confidential?

Health professionals currently involved in your care, including your G.P., will be informed that you are taking part in the study. We may wish to link information collected in this study to other health information on you e.g. hospital admissions. However, all information collected about you during the course of this study will be kept strictly secure and confidential.

Who is organising and funding the study?

Dr Robert Hunter, Consultant Psychiatrist, Research and Development Director for Greater Glasgow Primary Care NHS Trust, is organising the study. The study is being funded by a grant from the Clinical Resource and Audit Group (CRAG) of the Scottish Health Department in Edinburgh.

What will happen to the results of the study?

When the study is finished (in 2005) a report will be written which will be published in a medical journal. No individual patient will be identified in any report. Copies of a report on the study will be available from your keyworker.

Who has reviewed the study?

As well as mental health professionals, both the Scottish Association for Mental Health (SAMH) and the National Schizophrenia Fellowship (NSF) have reviewed the study.

Contact for further information

Rosie Cameron, National Project Co-ordinator, Research and Development Directorate, Gartnavel Royal Hospital, 1055 Great Western Road, Glasgow, G12 0XH.
Telephone: 0141 211 3582.

Thank you for taking the time to read this information sheet.



Scottish Schizophrenia Outcomes Study

CONSENT FORM

NHS Trust/Organisation: _____

Please tick
each box

1. I confirm that I have read, and understand, the information sheet dated March 2002 (version 3) for the above study and have had the opportunity to ask questions
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my medical care or legal rights being affected.
3. I give permission for my GP and /or any health care professional involved in my care to be told that I am participating in this study.
4. I give permission for the information collected in this study to be linked to other NHS data.
5. I agree to take part in the above study.

Name of Patient / Service User Date Signature
(please print)

Name of Keyworker taking consent Date Signature
(please print)

1 copy for service user; 1 copy for keyworker; 1 copy to be kept with case notes.

Responses to a questionnaire sent to a sample of keyworkers at the end of the study.

200 questionnaires sent out, with a response rate of 71% (n=142).

65% (92) of respondents were not using outcome measures prior to becoming involved in SSOS. The respondents who were using outcome measures reported to using a combination of HoNOS, Avon, FACE and Camberwell.

51% (73) reported using the outcome measures utilised in SSOS with other patients on their case load.

90% (128) reported that they would continue using outcome measures in routine practice at the end of the study period.

The outcome measures they reported using (or intending to use) include combinations of HoNOS, Avon, FACE and Camberwell with the majority favouring HoNOS and Avon.

79% (113) of respondents had cascaded information regarding the use of outcome measures to colleagues.

28% (40) had cascaded training. Interestingly 4 people who had cascaded training also reported that they would not be using outcome measures routinely at the end of the study period. This may indicate that these people have moved jobs, thus explaining why they will not be using the tools.

The following statements were included in the questionnaire and the responses are as indicated:

	Strongly agree / Agree	Unsure	Disagree/ Strongly Disagree	No Response
There is a need within mental health services to use some form of outcome measure	135 (95%)	7 (5%)	–	–
Service user needs assessments should be incorporated into the routine care management process	139 (98%)	2 (1.5%)	1 (.5%)	–
It became easier each year to complete an annual assessment for my participants involved in SSOS	114 (80%)	18 (13%)	7 (5%)	3 (2%)
Service users benefit from having the opportunity to assess their own needs	129 (91.5%)	12 (8.5%)	–	–
Participating in the SSOS project has had a positive effect on my clinical practice	113 (80%)	19 (13%)	7 (5%)	3 (2%)
My organisation actively promotes the use of outcome measures or service user needs assessments	90 (63%)	28 (20%)	23 (16%)	–

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SSOS Training Session

Agenda

- 09:30 Registration**
- 10:00 Introductions
Familiarisation with Keyworker Resource Pack
Study Overview
- 10:30 Avon Mental Health Measure
- User Centred Approach to Assessment of Need
- 11:30 HoNOS (Health of the Nation Outcome Scales)
- Clinically Rated Assessment Tool
Rating Scales
Score Sheets
- 12:30 LUNCH**
- 13:30 HoNOS Practical Session Using Video and Vignette
- 14:30 COFFEE**
- 14:45 HoNOS Practical Session Using Vignettes
- 15:15 Study Administration
- 15:45 Discussion and Feedback
- 16:30 CLOSE

HoNOS Score	Avon Score
Overactive, aggressive, disruptive or agitated behaviour <input type="checkbox"/>	Physical
Non-accidental self injury <input type="checkbox"/>	<input type="checkbox"/> Food
Problem drinking or drug taking <input type="checkbox"/>	<input type="checkbox"/> Shelter / Accommodation
Cognitive problems <input type="checkbox"/>	<input type="checkbox"/> Physical Health
Physical illness or disability problems <input type="checkbox"/>	<input type="checkbox"/> Self Care
Problems with hallucinations & delusions <input type="checkbox"/>	<input type="checkbox"/> ill Effects Of Treatment
Problems with depressed mood <input type="checkbox"/>	Social
Other mental & behavioural problems (specify A,B,C,D,E,F,G,H,I OR J) <input type="checkbox"/>	<input type="checkbox"/> Social Support
Problems with relationships <input type="checkbox"/>	<input type="checkbox"/> Discrimination
Problems with the activities of daily living <input type="checkbox"/>	<input type="checkbox"/> Daily Routine
Problems with living conditions <input type="checkbox"/>	<input type="checkbox"/> Community Involvement
Problems with occupation & activities <input type="checkbox"/>	Behaviour Record Bad Day
Total Score <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> Sleep Disturbance
	<input type="checkbox"/> Risk To Self
	<u>Substance Misuse</u>
	<input type="checkbox"/> Alcohol
	<input type="checkbox"/> Drugs
	<input type="checkbox"/> Suicide
	<input type="checkbox"/> Anger
	Access Record Bad Day
	<u>Transport</u>
	<input type="checkbox"/> Availability
	<input type="checkbox"/> Physical Access
	<u>Information</u>
	<input type="checkbox"/> Availability
	<input type="checkbox"/> Understanding
	<input type="checkbox"/> Communication
	<input type="checkbox"/> Income
	<input type="checkbox"/> Managing Money
	Mental Health Record Bad Day
	<input type="checkbox"/> Mood Swings
	<input type="checkbox"/> Depression
	<input type="checkbox"/> Unusual Thoughts & Experiences
	<input type="checkbox"/> Anxiety Or Fear
	<input type="checkbox"/> Obsessive thinking/Compulsive Activities
	<input type="checkbox"/> Problems with Forgetting & Understanding
Setting where rated (enter one number only) <input type="checkbox"/>	
1 ACUTE	
2 LONG STAY (INCLUDING FORENSIC SERVICE)	
3 DAY HOSPITAL	
4 DAY CENTRE	
5 OUT-PATIENT DEPARTMENT	
6 OWN HOME	
7 OTHER: _____	

On completion, please send in to the SSOS Office along with a copy of the signed consent form.

(NB – Not to scale)



Scottish Schizophrenia Outcomes Study

National Meeting

12 June 2003

Programme

09:30 REGISTRATION

- 10:00 Chairman's Welcome and Introduction
Dr Robert Hunter, Consultant Psychiatrist
- 10:10 NHS Quality Improvement Scotland: Schizophrenia Review
Sean Doherty, Review Team Manager, NHS Quality Improvement Scotland
- 10:25 Improving Mental Health
Dr Alastair Valentine Philp, Programme Manager, ISD Scotland
- 10:40 *Question & Answer Session*
- 10:50 COMFORT BREAK**
- 11:05 SSOS: The Organisational Perspective
Andrew Dickson, Head of Nursing (MH & LD), Renfrewshire & Inverclyde PCT
- 11:20 SSOS: A Community Mental Health Team Perspective
Avril Herries & Denise Moffat, Community Psychiatric Nurses, Stewartry CMHT, Dumfries
- 11:35 SSOS: Involving Service Users
Jim Kiddie, SNP Councillor, Aberdeen
- 11:50 *Question & Answer Session*
- 12 noon LUNCH**
- 13:00 - 14:00 Workshops
- Workshop 1** *Mental Health Outcome Measures: In-patient Services*
Workshop 2 *Mental Health Outcome Measures: Community Settings*
Workshop 3 *Mental Health Outcome Measures: Community Settings*
Workshop 4 *Mental Health Outcome Measures: Rehabilitation Services*
- 14:00 TEA/COFFEE BREAK**
- 14:35 The Role of Outcome Measures within Integrated Care Pathway's for Schizophrenia
Mark Fleming, Clinical Development Manager, North Ayrshire
- 15:00 SSOS: The First Phase – Feedback
Rosie Cameron, Project Manager
John Norrie, Statistician, Centre for Biostatistics, University of Glasgow
- 15:40 Chairman's Closing Remarks
Dr Robert Hunter



2nd National Meeting

'Improving Clinical Outcomes for People with Schizophrenia'

7th October 2004
Stirling Management Centre

Programme

09:30 - 10.00	Registration	<i>Tea/Coffee on arrival</i>
10:00 - 10:10	Chairman's welcome and opening remarks	<i>Prof Robert Hunter</i>
10:10 - 10:35	Project Update - where are we now?	<i>Rosie Cameron</i>
10:35 - 10:55	Data Feedback and Evaluation	<i>John Norrie Andrew Walker</i>
10:55 - 11:10	Question & Answer Session	
11:10 - 11:25	Comfort Break - cold refreshments in the conservatory	
11:30 - 12:30	BREAKOUT SESSION 1	
12:30 - 13:30	LUNCH and POSTERS	
13:30 - 14:30	BREAKOUT SESSION 2	
14:35 - 15:00	NHS QIS Mental Health Work Programme	
	- <i>What has been achieved?</i>	<i>Dr John Loudon</i>
	- <i>Where do we go next?</i>	<i>Sean Doherty</i>
15:00 - 15:15	Question & Answer Session	
15:15 - 15:30	Closing Remarks	<i>Prof Robert Hunter</i>
15:30	<i>One for the Road.....Tea/Coffee/Networking</i>	

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National Conference

'Working to Improve Clinical Outcomes For People With Schizophrenia'

Date: Friday 4th November 2005
Venue: Atholl Palace Hotel, Pitlochry, Perthshire

09:30 - 10.00 Registration *Tea/Coffee on arrival*

Why do we need to use Outcome Measures?

10:00 - 10:10 Chairman's welcome and opening remarks
Dr David Steel, Chief Executive, NHS Quality Improvement Scotland

10:10 - 10:25 Keynote speaker - *Professor Michele Tansella, University of Verona*

What did we learn from SSOS ?

10:25 - 11:15 SSOS Journey Perspectives from:

- The Project Team - What worked well and what didn't *Rosie Cameron & Bob Hunter*
- Service Managers - Making SSOS happen locally *Jan Jamieson & Barry Sharp*
- Keyworker - How SSOS influenced change *Marie Simpson*

11:15 - 11:30 Break - *refreshments available upstairs outside the Bow Lounge*

11:30 - 12:15 Key Findings from SSOS
Professor Robert Hunter, Project Convenor and John Norrie, Director, CHaRT, Aberdeen

12:15 - 12:30 Question & Answer Session

12:30 - 13:30 LUNCH SERVED IN THE RESTAURANT

Experiences from around the world

13:30 - 13:45 The Italian Job
Dr Antonio Lasalvia, Senior Registrar, Department of Medicine, University of Verona

13:45 - 14:00 The English Experience of Implementing Outcomes - Has it really all gone wrong?
Mick James, National HoNOS Advisor, College Research & Training Unit

14:00 - 14:15 The Canadian Implementation of HoNOS
Professor Stephen Kisely, Chair, Health Outcomes, Dalhousie University

14:30 - 14:45 Break - *refreshments available upstairs outside the Bow Lounge*

Vision for the future?

14:45 - 15:00 'Outcomes and Assessment - a recovery perspective'
Simon Bradstreet, Scottish Recovery Network

15:00 - 15:15 NHS Quality Improvement Scotland - Mental Health Strategic Work Programme
Dr John Loudon, Mental Health Advisor, NHS Quality Improvement Scotland

15:15 - 15:45 Panel Discussion on Future National Strategy and Implementation of Outcomes
An opportunity for delegates to put their questions to the panel of experts

15:45 - 16:00 Closing Remarks and Key Recommendations from SSOS
Professor Robert Hunter

***Examples of good practice in the use of outcome measures
from local areas that participated in SSOS***

- **Ayrshire and Arran** have an electronic Integrated Care Pathway (ICP) based on FACE assessments and incorporates outcome measures.
- In **Grampian** the Schizophrenia Standards Group incorporated Avon into the design of their single shared assessment, and the Forensic Service plan to incorporate Avon into their routine assessment process. SSOS provided dedicated training events to assist with the roll-out of Avon in Aberdeen City and Aberdeenshire.
- Within **Lanarkshire**, the Hamilton CMHT have incorporated HoNOS and Avon within their multidisciplinary team.
- In **Glasgow** HoNOS is one of the locally agreed clinical rating tools for routine use and most community staff based within resource centres routinely record scores in PiMS (Patient Information Management System). Avon is also available via PiMS and is now being more widely used in various localities e.g. Larkfield Resource Centre utilize AVON within the Global Health Clinic; Shawpark Resource Centre has introduced Avon for all patients.
- Within **Dumfries & Galloway** HoNOS is utilised within the ICP for schizophrenia.
- In **Borders**, the Community Rehabilitation Team utilises CANSAS, a shortened form of the Camberwell Assessment of Need, completed by clinicians.
- **Forth Valley** utilise the paper based FACE assessments in routine practice.
- Within **Highland**, SSOS delivered extra training in the use of HoNOS to both nursing and medical staff. Local trainers are currently rolling out training in HoNOS to all community staff as an element of their Integrated Care Pathway (ICP). Caithness has piloted Avon for all patients within their CMHT.
- In **Tayside**, Dundee has piloted Avon and HoNOS and this is currently being evaluated. SSOS delivered 'training for trainers' in the use of HoNOS for staff covering Forfar, Arbroath and Angus with the aim of local trainers rolling out training to all staff in the CMHTs. One CMHT in Perth is now utilising Avon for all patients.
- At St Johns Hospital in **West Lothian** the admission ward has incorporated Avon and HoNOS into their process of care and community based teams are using Avon.