

Psychiatric compulsion and long-term social outcomes for patients with psychosis: is there an association?

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Abstract

Compulsory interventions are widely used in general adult psychiatry for the treatment and care of patients with severe mental illness. While involuntary hospitalisation is established in practice around the world, the use of compulsory interventions outside of hospital – so called community treatment orders (CTOs) – is a more recent development. Three randomised controlled trials of CTO effectiveness have been conducted to date finding no benefits for patients in terms of reduced relapse and readmission to hospital. However, these trials have been relatively short (11-12 months) and focused almost exclusively on CTO effects on clinical functioning and service use. Little attention has been given to patients' social outcomes and broader welfare despite their recognised importance. A sub-sample (n = 121) from the Oxford Community Treatment Order Evaluation Trial (OCTET) were interviewed 48-months after randomisation to assess whether the duration of the CTO intervention was associated with more or less favourable social outcomes at follow-up. Social outcomes were assessed using three main concepts: social networks (Study 1), social inclusion (Study 2), and capabilities (Study 3). No significant associations between the duration of the CTO intervention and social outcomes at follow-up were found. The association between involuntary hospitalisation and social outcomes was also tested but no significant associations were found. Because the field of social outcome measurement is relatively undeveloped, a further aim was to contribute to the validation and testing of two recently developed instruments: the Social and Community Opportunities Profile (SCOPE) (Study 4) and the Oxford Capability Questionnaire for Mental Health (OxCAP-MH) (Study 5). The SCOPE performed well overall as a measure of social inclusion but questions were raised about its feasibility (length) and the reliability of one of its sub-scales. The OxCAP-MH demonstrated good psychometric properties (reliability and validity) and represents a promising new multi-dimensional patient-reported outcome measure for use in mental health research.

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Table of Contents

Abbreviations **1**

Chapter 1: Introduction **2**

1.1 Background and rationale 2

1.2 Pressures, coercion and compulsion in psychiatry 5

1.2.1 Justification for the use of compulsion 8

1.2.2 Who is coerced? 11

1.3 Does compulsion work? 14

1.3.1 Outcomes of involuntary hospitalisation 14

1.3.2 Effectiveness of community compulsion 16

1.3.3 Is compulsion harmful? 18

1.4 Outcomes measurement in psychiatry 19

1.4.1 Social outcomes 20

1.4.2 Measuring social outcomes 20

1.4.3 Social functioning measures for patients with psychotic illnesses 22

1.5 The current study: OCTET Social Outcomes Study 24

1.5.1 Background: The OCTET Trial 24

1.5.2 Conceptualisation and measurement (Studies 1 to 3) 25

1.5.3 Instrument validation (Studies 4 and 5) 30

1.5.4 Study rationale and hypotheses (Studies 1 to 3) 31

1.6 Research questions 35

Chapter 2 Social networks and psychiatric compulsion **37**

2.1 Introduction 37

2.1.1 Background 37

2.1.2 Social ties and health 38

2.1.3 Social networks and psychosis 40

2.1.4 Social networks and illness: cause or consequence? 40

2.1.5 Mechanisms 41

2.1.6 Measuring social networks 43

2.1.7 Improving social networks 45

2.1.8 Psychiatric compulsion and social networks (Study 1) 46

2.2 Research questions....47
2.3 Methods....48
2.3.1 Sample....48
2.3.2 Power calculation....51
2.3.3 Design and procedure....51
2.3.4 Instruments used in the study....52
2.3.5 Data management....55
2.3.6 Statistical analyses....55
2.4 Results....58
2.4.1 Participant flow and follow-up....58
2.4.2 OCTET Social Outcomes Study baseline characteristics....60
2.4.3 Interventions during follow-up....64
2.4.4 Characteristics of social networks....66
2.4.5 Principal findings....68
2.4.6 Subsidiary findings....69
2.4.7 Social network size and clinical functioning....76
2.5 Discussion....78
2.5.1 Main findings....78
2.5.2 Social network characteristics....80
2.5.3 Social network and functioning....81
2.5.4 Compulsion and clinical functioning during follow-up....82
2.5.5 Strengths and limitations....83
2.5.6 Limitations of the OCTET Social Outcomes Studies (Studies 1 to 3)....85
2.5.7 Conclusions....88
Chapter 3: Social inclusion and psychiatric compulsion....89
3.1 Introduction....89
3.1.1 Background: from exclusion to inclusion....89
3.1.2 A conceptual history: exclusion or inclusion?....93
3.1.3 Measuring social inclusion in mental health research....97
3.1.4 Psychiatric compulsion and social inclusion (Study 2)....100
3.2 Research questions....101
3.3 Methods....103
3.3.1 Instruments used in the study....103

3.3.2 Statistical analyses 104
3.4 Results 106
3.4.1 Principal findings 107
3.4.2 Subsidiary findings 110
3.5 Discussion 120
3.5.1 Main findings 120
3.5.2 Subsidiary findings 121
3.5.3 Comparisons with previous studies and the general population 122
3.5.4 Strengths and limitations 123
3.5.5 Summary 125
Chapter 4: Capabilities and psychiatric compulsion 126
4.1 Introduction 126
4.1.1 The capability approach 126
4.1.2 Patient reported outcome measures 128
4.1.3 Applications of the capability framework 130
4.1.4 Psychiatric compulsion and capabilities (Study 3) 135
4.2 Research questions 136
4.3 Methods 137
4.3.1 Instruments used in the study 137
4.3.2 Statistical analyses 138
4.4 Results 140
4.4.1 Principal findings 141
4.4.2 Subsidiary findings 143
4.5 Discussion 148
4.5.1 Principal findings 148
4.5.2 Subsidiary findings 149
4.5.3 Summary 153
Chapter 5: A critical evaluation of the SCOPE 154
5.1 Introduction 154
5.1.1 Background 154
5.1.2 The SCOPE 155
5.2 Research questions 157

5.3 Methods 157
5.3.1 Instruments used in the study 157
5.3.2 Statistical analyses 159
5.4 Results 161
5.4.1 Feasibility 162
5.4.2 Reliability of the SCOPE sub-scales 162
5.4.3 Construct validity of the SCOPE sub-scales 163
5.4.4 Sub-scale correlations with subjective perception of social inclusion 165
5.5 Discussion 165
5.5.1 Feasibility 165
5.5.2 Reliability of the SCOPE sub-scales 166
5.5.3 Validity of the SCOPE sub-scales 168
5.5.4 Content validity of the SCOPE 171
5.5.5 Objective indicators of social inclusion 172
5.5.6 Study limitations 175
5.5.7 Summary and conclusions 175
Chapter 6: Psychometric validation of the OxCAP-MH 177
6.1 Introduction 177
6.1.1 Background 177
6.1.2 Psychometric properties 178
6.2 Research questions 181
6.3 Methods 182
6.3.1 Sample 182
6.3.2 Design and procedure 182
6.3.3 Instruments used in the study 183
6.3.4 Statistical analyses 184
6.4 Results 188
6.4.1 Sample characteristic 188
6.4.2 Floor and ceiling effects 193
6.4.3 Reliability of the OxCAP-MH 193
6.4.4 Validity of the OxCAP-MH 194
6.4.5 Sensitivity to change 195
6.4.6 Objective capability ratings 202

6.5 Discussion 202
6.5.1 Main findings 202
6.5.2 Sensitivity to change 204
6.5.3 Distribution of OxCAP-MH scores 207
6.5.4 Patient-rated vs. objectively-rated capabilities scores 208
6.5.5 Strengths and Limitations 208
6.5.6 Summary 210
Chapter 7: Summary and implications 211
7.1 Introduction 211
7.2 Summary of empirical findings 212
7.3 Understanding the association between CTOs and social outcomes 215
7.4 Involuntary hospitalisation and social outcomes 222
7.5 CTOs: Implications for clinical practice and policy 223
7.6 Remarks on social outcome measures 225
7.7 Closing remarks 228
References 230
Appendices 259
Appendix I: Patient interview booklet (48-months follow-up) 259
Appendix II: Floor and ceiling effects for OxCAP-MH 294
Appendix III: OxCAP-MH individual item correlations 295

Abbreviations

AES	McArthur Admission Experience Survey
AES – PC	McArthur Admission Experience Survey – Perceived Coercion
BPRS	Brief Psychiatric Rating Scale
CI	Confidence interval
CMHT	Community Mental Health Team
CTO	Community Treatment Order
EQ-5D	European Quality of Life Measure (also EuroQol)
GAF	Global Assessment of Functioning
ICECAP-A	ICEpop CAPability measure for Adults
IRR	Incident rate ratio
MHA	Mental Health Act
NHS	National Health Service
NICE	National Institute for Health and Clinical Excellence
NIHR	National Institute for Health Research
ONS	Office for National Statistics
OxCAP-MH	Oxford Capability Questionnaire – Mental Health
PROM	Patient Reported Outcome Measure
QALY	Quality Adjusted Life Year
RCT	Randomised Controlled Trial
SCOPE	Social and Community Opportunities Profile
SD	Standard deviation
SIX	Objective Social Outcomes Index
SNS	Social Network Schedule
SPSS	Statistical Package for the Social Sciences
UN	United Nations

Chapter 1: Introduction

Power is held accountable, and deliberation is conducted in public

– *Herodotus*

1.1 Background and rationale

The involuntary detention and treatment of people with mental illness has been practiced since ancient times, yet for most of human history these individuals have received little in the way of formal treatment, support and care. Starting in medieval Europe, informal shelters and homes gradually gave way to the first purpose-built 'asylums', such as the Bethlem Hospital in England, built to house and treat the severely mentally ill. The early 19th century ushered in the modern era of institutionalised psychiatric care and saw the construction of hundreds of hospitals across Europe and North America and, for nearly one and half centuries, this was considered the most humane and effective way to care for the mentally ill (Fakhoury and Priebe, 2002). Many patients lived much of their lives in these hospitals.

Starting in the 1950s with the introduction of novel psychotropic medications, the early civil rights movements, and the development of alternative community-based mental health services, models of care built around the asylum were gradually

reformed (McCulloch et al., 2000). Many of the former long-stay psychiatric hospitals were closed in favour of community-based services and more than half a million long-stay patients have since been discharged from hospitals in the United Kingdom and United States alone (Brown, 1981; Chow and Priebe, 2013; Leff et al., 1995).

This process of 'deinstitutionalisation' played an important role in tackling some of the problems of the old asylums such as social isolation, stigma and discrimination, but it created new challenges for patients and health services. Many former long-stay patients lacked the skills or support to live independently in the community, resulting in large numbers becoming homeless, trapped within the criminal justice system, or caught in a cycle of frequent relapse and readmission to hospital. This cycle of relapse and readmission to hospital has been referred to as the 'revolving door' problem (Dawson, 2005; Geller, 2000). One response to the revolving door problem was the introduction of legally mandated community treatment, referred to as *community treatment orders* (CTO) in England and Wales (known elsewhere as Assisted Outpatient Treatment, Mandated Outpatient Treatment, Supervised Community Treatment, or Outpatient Commitment).

CTOs provide a legal framework within which patients with severe mental illness can be required to accept treatment while living in the community (Churchill et al., 2007). They were introduced on the basis that they would improve patient engagement with services, increase adherence with medication and reduce relapse and readmission, while also serving as a less restrictive alternative to hospitalisation. CTOs require a patient to adhere to the conditions stipulated in their treatment order, such as taking their medication and meeting with a mental health professional; if the patient fails to meet these conditions and is perceived to be relapsing, they can be rapidly recalled to

hospital for assessment and, if necessary, readmission for treatment (Churchill et al., 2007).

CTOs were introduced in England and Wales in 2008 following amendments to the Mental Health Act (Burns and Molodynski, 2014; MHA, 2008). A lack of evidence supporting their effectiveness has polarised debates about their use (Burns and Dawson, 2009). Two previous randomised controlled trials (RCT) of CTO effectiveness conducted in the United States found no benefits in terms of reduced rates of relapse and readmission (Steadman et al., 2001; Swartz et al., 1999). The Oxford Community Treatment order Trial (OCTET), conducted in England, was the third and largest test of CTO effectiveness, but again found no evidence of clinical or social benefits for patients (Burns et al., 2013; Rugkåsa et al., 2014b).

All three RCTs have been relatively short (11 – 12 months) and have focused almost exclusively on service use (readmission to hospital) and clinical outcomes (symptoms). There has been little critical discussion and empirical evaluation of the relationship between CTOs and social outcomes including patients' broader welfare, despite persistent calls for these outcomes to be given greater prominence when evaluating interventions for patients with psychotic illnesses (Kisely et al., 2013; Priebe, 2007; Tulloch et al., 2006).

This DPhil thesis extends the OCTET programme of research to test the association between the duration of CTO treatment and social outcomes at 48-months follow-up using three main concepts: social networks, social inclusion and capabilities. Outcomes were assessed using the Social Network Schedule (*Chapter 2*), Social and Community Opportunities Profile (SCOPE) (*Chapter 3*), and the Oxford Capability Questionnaire – Mental Health (OxCAP-MH) (*Chapter 4*). Assessing social outcomes

is highly relevant for patients with psychotic illnesses and has been increasingly called for by stakeholder groups (Frick et al., 2013; Kisely et al., 2014; Priebe, 2007; Tulloch et al., 2006), yet measures to assess these outcomes remain relatively undeveloped. A further aim of this DPhil was therefore to contribute to the validation and testing of two recently developed social outcomes measures, namely the SCOPE (*Chapter 5*) and OxCAP-MH (*Chapter 6*). A summary and discussion of the empirical findings, including the clinical and policy implications, is contained in *Chapter 7*.

1.2 Pressures, coercion and compulsion in psychiatry

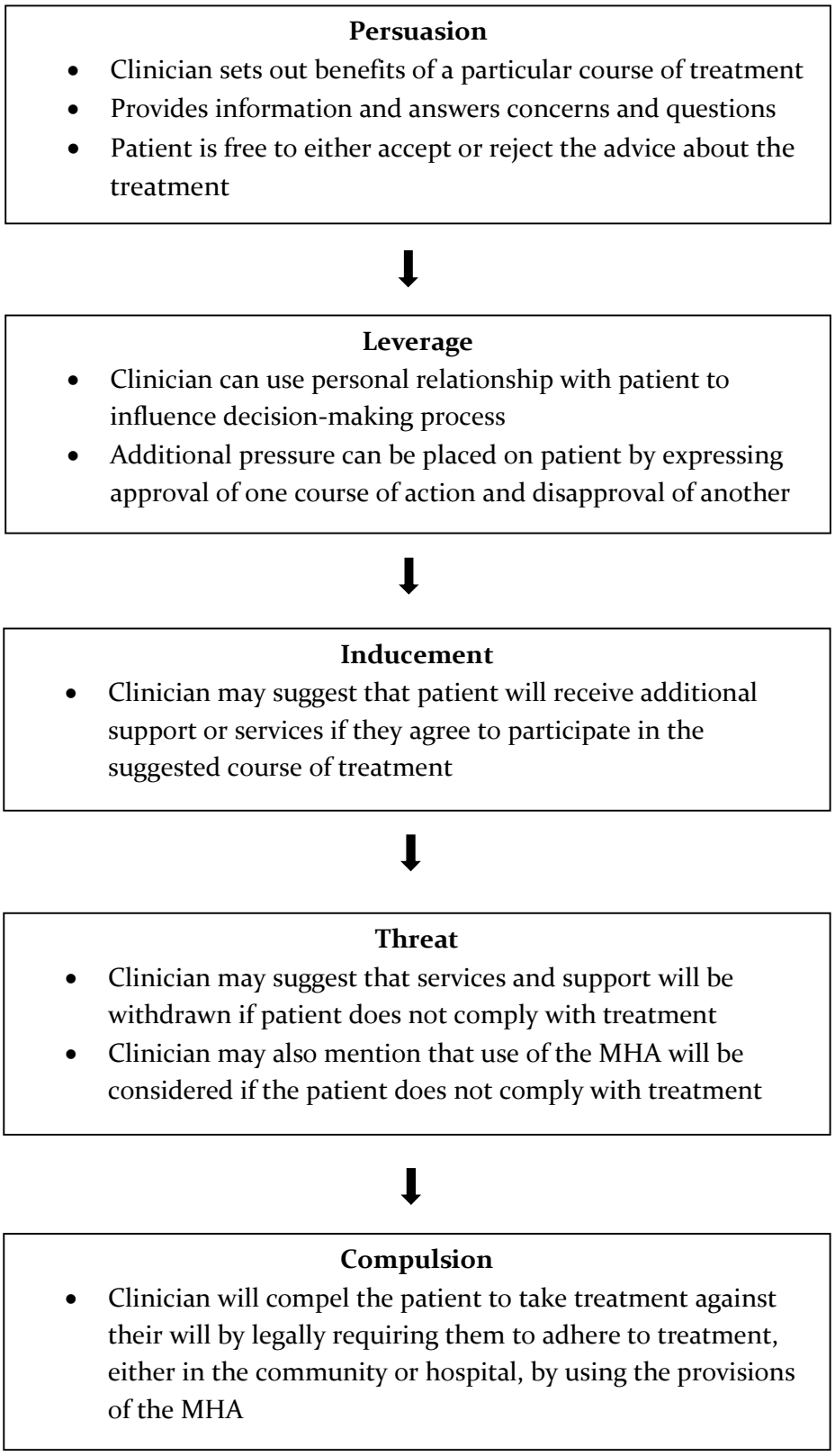
The use of compulsory hospitalisation and non-consensual treatment is one of the defining features of psychiatry. The practice is unique to the psychiatric medical specialty and exists in some form in virtually every country in the world (Kallert et al., 2008; Priebe, 2007; Salize and Dressing, 2004). The clinical appropriateness and ethical justification for the use of non-consensual treatment has been the source of considerable past and ongoing controversy (e.g. Høyer, 2000; Molodynski et al., 2010; Szasz, 1998; Wynn, 2006). These debates have generally centred on three main problems: civil liberties (including patient autonomy), mental capacity, and the need for treatment.

Patient autonomy is one of the overarching principles in modern Western bioethics (Gillon, 1994). The principle recognises the right of an individual to self-determination and includes the right to decide whether or not to accept treatment. Although refusal of treatment may occur in any medical specialty, it rarely raises serious ethical or legal issues because the patient is generally considered to have the capacity to decide

whether or not they wish to take treatment. Under these circumstances there is little doubt that it would be unethical to impose treatment against the patient's will. In psychiatric practice, however, situations in which patients refuse to accept treatment are more likely to raise ethical dilemmas. This is because the capacity of a patient to make decisions about their treatment is more likely to be questioned when they are suffering from a mental illness.

In clinical practice, a patient who is judged to require treatment in their 'best interest' but who lacks the capacity to decide whether or not to accept it, may be subject to various 'pressures' (coercion) in order to encourage them to accept treatment. Szmukler (2008) has described the use of coercion in a mental health context as 'a spectrum of pressures … exerted to gain the patient's cooperation with treatment' (p.457) (see **Figure 1**). These pressures can range from persuasion, interpersonal leverage, inducements (offers), threats, through to the use of formal (legal) compulsion under the law (Molodynski et al., 2010; Szmukler and Appelbaum, 2008). Thus, at one end of the spectrum, a clinician might try to persuade a patient to accept treatment by providing information about the pros and cons of the treatment while leaving the them free to decide whether or not to accept it; at the other end, the clinician may invoke the power of the law to compel or force a patient to remain in hospital and take treatment.

Figure 1 Hierarchy of treatment pressures



Adapted from Molodynski et al. (2010)

Terminology

This DPhil focuses on the use of formal or legal coercion. This is referred to as *compulsion*. The term *coercion* is employed generically to refer to any form of pressure, force or threat of force, legal or otherwise, that may be used to encourage or enforce adherence with treatment. The terms *community treatment order (CTO)* and *community compulsion* will be used interchangeably, as will the terms *involuntary hospitalisation, involuntary detention* and *hospital compulsion*. Because studies show that a patient's perception of being coerced does not necessarily correlate with the use of legal compulsion (e.g. Gilboy and Schmidt, 1971; Monahan et al., 1996), the term *perceived coercion* is used to refer to the patient's subjective experience of the coerciveness of their treatment and care, distinct from 'objectively' coercive events (such as involuntary admission) which may or may not influence the patient's perception of coercion. *Informal coercion* refers to pressures imposed by mental health professionals, family members, carers, housing providers, etc., in order to encourage adherence with treatment (Molodynski et al., 2010) (see **Figure 1**).

1.2.1 Justification for the use of compulsion

The use of compulsion is the most publicly visible and controversial form of coercion used in mental healthcare. This is because compulsion raises various ethical problems about whether, and under what circumstances, such treatment could, or indeed should, be permissible. Although mental health professionals, legal experts and philosophers broadly agree that the use of compulsion is sometimes justifiable

(Høyer, 2000), there remains a lack of consensus around the precise conditions under which it should be permitted. There are generally two conditions under which non-consensual treatment or compulsion is considered justified (Szmukler and Appelbaum, 2008):

1. Treatment is in the health interests of the patient, or
2. Treatment is needed for the protection of others

The condition of protection can be applied in the best interests of the patient (e.g. to prevent serious self-harm or suicide) but can also be applied in the protection of the public (often the patient's family) from perceived dangerous or threatening behaviour. The condition of need for treatment – which can include the need for and protection from self-neglect – is always applied in the patient's best interests (Høyer, 2000).

There is broad agreement internationally that a confirmed mental disorder is a necessary condition for involuntary detention, although various additional criteria vary by country and jurisdiction. Some stipulate the risk to self or others while others emphasise lack of insight or the need for treatment (Salize and Dressing, 2004). In the UK, the use of extended involuntary hospital detention (>28 days) is only permitted where effective treatment is known to be available from which the patient might benefit (MHA, 2008).

Community compulsion

As the use of community compulsion has become more frequent and widespread internationally, debates about its clinical effectiveness and ethical justification have

come into focus (Lawton-Smith, 2005; O'Brien, 2014). CTOs have been defined as 'a compulsory community-based treatment order (which) requires a patient to comply with a set of conditions, such as taking their medication, while allowing them to live in the community' (Lawton-Smith, 2005, p.8). CTOs were introduced in England and Wales in November 2008 following amendments to the Mental Health Act 1983 (MHA, 2008). Within this framework CTOs can only be applied to patients who are currently detained under the MHA (Section 3 or equivalent forensic sections). Once on a CTO, the patient is required to meet the conditions set out in their treatment order, such as to remain adherent with medication and to meet with the mental health team. If they are believed to be relapsing, they can be *recalled* to hospital and held for up to 72 hours for a mental health assessment. The mental health assessment has three possible outcomes: (1) the patient is admitted to hospital for treatment or further assessment, in which case the CTO is revoked and Section 3 is reinstated; (2) the patient is discharged back into the community and remains on the CTO; (3) the CTO is rescinded (usually the decision of the responsible clinician), in which case they are no longer restricted under the MHA.

Given the restrictiveness of CTOs, their use has generated considerable controversy and debate (Høyer, 2000, Molodynski et al., 2010; Szasz, 1998; Wynn, 2006). Those in favour of CTOs have generally argued that they offer a less restrictive alternative to involuntary hospitalisation and consequently represent a more ethical treatment choice (Hiday, 2003; Lawton-Smith et al., 2008). CTOs have been seen as especially justifiable for patients who have a history of multiple hospital admissions and of losing capacity to consent to treatment when unwell (Dale, 2010). Critics have described CTOs as paternalistic and discriminatory and likely to increase levels of overall use of coercion, further diminishing freedom of choice for people with mental illnesses

(Lawton-Smith et al., 2008). Debates about the justification for the use of CTOs have been plagued by either a lack of evidence supporting their effectiveness (Burns and Dawson, 2009) or how the existing evidence is interpreted (Burns and Molodynski, 2014; Curtis, 2014; Mustafa, 2014; Rugkåsa and Dawson, 2013; Rugkåsa et al., 2014a).

1.2.2 Who is coerced?

Inpatient compulsion

The prevalence of hospital compulsion appears to vary widely by country and jurisdiction, though reliable data are often scarce and there are no common international reporting standards (Dressing and Salize, 2004; Wynn, 2006). Estimates of compulsory admissions range from prevalence as low as 10% in a US inpatient sample (Hoge et al., 1997) to 100% in an Icelandic sample (Kjellin et al., 2006); data from an unpublished systematic review of 18 papers suggests prevalence rates of around 50% (see Newton-Howes, 2010). Across the European Union, involuntary detention rates have been shown to vary markedly from 6 per 100,000 population in Portugal to 218 per 100,000 in Finland (Salize and Dressing, 2004). In the UK, 18,166 were detained in hospital on longer term hospital orders (>72 hours) for the 2013/2014 period, a rate of 35 per 100,000 (Health and Social Care Information Centre, 2015).

Data linking socio-demographic factors and increased risk of hospital compulsion are mixed (Newton-Howes, 2010). Studies in the UK have shown an increased risk of hospital compulsion among black and ethnic minorities and the elderly (Bindman et al., 2005) with a New Zealand and large US study reporting the reverse (Lidz et al.,

1995; McKenna et al., 2003). Similarly, contradictory evidence has been found for age and gender (Iversen et al., 2007; Poulsen, 1999), psychopathology (Iversen et al., 2002; Link et al., 2008; Monahan et al., 2001; Poulsen, 1999), overall functioning (Nicholson et al., 1996; Svensson and Hansson, 1994), and satisfaction with care (Iversen et al., 2007; Svensson and Hansson, 1994).

Community compulsion

Compared to the use of hospital compulsion, the use of community compulsion is far less widespread internationally. There are currently around 75 jurisdictions internationally that permit mandated community treatment, the majority of which are in high-income Western countries (Maughan et al., 2014). Prevalence rates of community compulsion vary widely between countries (Churchill et al., 2007; Durham and Pierce, 1986; O'Brien, 2014; Zinkler and Priebe, 2002). Estimates from 2005 show a range from around 2 per 100,000 population in Ontario and Saskatchewan, Canada, and New York State in the United States, to between 40–60 per 100,000 population in the Australian states of Queensland and Victoria, the District of Columbia in the United States, and New Zealand (Lawton-Smith, 2005). Regardless of the jurisdiction, the use of CTOs has steadily increased year on year: in the Australian state of Victoria, between 1993 and 2000, the number of patients on CTOs increased from 1,255 to 2,260; in New Zealand, the number rose from 1,207 in 1998 to 1,769 in 2003; in Tennessee, United States, the number increased tenfold from around 50 per year in the early 1980s to over 500 in 2005 (Lawton-Smith, 2005). More recent figures support this continued trend: data from a New Zealand sample show that national average rates increased from 58 per 100,000 population in 2005 to 85 per

100,000 in 2011 (O'Brien, 2014), while data from the state of Victoria reported prevalence rate of 99 per 100,000 population for the 2010/11 period (Light et al., 2012). In England and Wales, 5,365 people were subject to CTOs in 2013/2014, an increase of 6 % compared to 2012/2013 and a 32% increase since 2008/2009, the year CTOs were first introduced (Health and Social Care Information Centre, 2015).

The clinical and socio-demographic characteristics of patients subjected to community compulsion are remarkably similar across countries and jurisdictions (Churchill, 2007). A typical patient based on a summary of 14 studies:

- Male
- Around 40 years of age
- Long history of schizophrenia like illness
- Previous admissions
- Previous medication non-compliance
- Aftercare needs
- Potential for violence
- Displaying psychosis, in particular delusions
- Substance use (O'Brien and Farrell, 2005)

This pattern of patient characteristics has been confirmed by subsequent studies of CTO effectiveness (e.g. Burns et al., 2013).

1.3 Does compulsion work?

Despite its widespread use, the harms or benefits of compulsory interventions have been subject to relatively few empirical investigations (Dressing and Salize, 2004; Lelliott and Quirk, 2004; Sailas and Fenton, 2002). The most frequently reported outcomes used in studies of compulsion are readmission to hospital (Kent et al., 1995), time spent in hospital, psychopathological symptoms, and adherence to treatment (Salize and Dressing, 2005). Much less attention has been given to patients' social outcomes however (Tulloch et al., 2006).

1.3.1 Outcomes of involuntary hospitalisation

Robust studies reporting the outcomes of involuntary hospitalisation are scarce; of those that exist, nearly all come from high-income Western countries (Kallert et al., 2008). The first published systematic review identified 18 relevant studies, with considerable variation in quality, 15 of which were rated as being of low or medium quality (Katsakou and Priebe, 2006). Most involuntarily admitted patients were found to show substantial improvement in terms of symptoms and/or functioning at discharge from hospital and within the subsequent four months. Between 33% and 81% of patients retrospectively regarded their admission as justified and/or the treatment as beneficial (patients who showed greater improvement also tended to have more favourable retrospective evaluations). Socio-demographic and clinical predictors of more or less favourable clinical outcomes were mixed and inconclusive.

Kallert and colleagues (2008) compared outcomes of acute hospitalisation for voluntarily and involuntarily admitted patients, also finding that the overall methodological quality of studies was on average quite low. Only limited differences in outcome for voluntary and involuntary patients were found; however, involuntarily admitted patients showed lower levels of social functioning and higher suicide rates, and were more likely be dissatisfied with treatment and to feel that the treatment was unjustified (Kallert et al., 2008). A more recent multi-centre study in 11 European countries reported that one month following their admission patients showed significantly improved symptoms with further improvement at three months (Kallert et al., 2011). The size of the improvement was described as 'moderate', however, with substantial inter-individual variation. Higher baseline symptoms, being unemployed, living alone, multiple previous hospitalisations, and being initially less satisfied with treatment were all associated with less symptom improvement after one month and, other than initial treatment satisfaction, also after three months.

One of the few prospective studies to test predictors of both clinical and social outcomes following involuntary hospitalisation showed that, at one year follow-up, symptom levels and global functioning had improved moderately, subjective quality of life had a small but significant improvement, while objective social outcomes had a small but statistically significant deterioration (Priebe et al., 2011). Patients' initial experiences of treatment, in terms of perceived coercion or satisfaction with treatment were predictive of outcome at one year follow-up. The authors conclude that, following involuntary admission, patients showed on average 'only limited health and social gains' over the one year follow-up (p.377).

1.3.2 Effectiveness of community compulsion

The effectiveness of community compulsion has been the subject of protracted debate, mostly with little evidence to support either camp (Burns and Dawson, 2009). Although early evaluations of CTOs demonstrated favourable clinical outcomes in terms of reduced hospital utilisation (Bursten, 1986; Fernandez and Nygard, 1990; Geller, 1990; O'Keefe et al., 1997; Sensky et al., 1991; Van Putten et al., 1988; Zanni and DeVeau, 1986), many of these studies have been criticised on methodological grounds (e.g. O'Reilly, 2001), and were not randomised (and often not controlled either), making it difficult to draw conclusions about causality. Evidence from the first two RCTs (and ensuing follow-up studies) conducted in the United States suggested that CTOs may improve outcomes in some domains, although no significant effect in their primary outcomes were found (the New York study was significantly flawed while the North Carolina study found a significant result only in a post hoc analysis) (Rain et al., 2003; Steadman et al., 2001; Swartz et al., 1999; Swartz et al., 2002). A subsequent Cochrane review which included data from the RCTs concluded that there was 'little evidence of efficacy on any outcomes such as health service use, social functioning, mental state, quality of life or satisfaction with care' (Kisely et al., 2005, p.2). A review of the international literature conducted shortly thereafter concluded that it was not possible to establish whether CTOs are beneficial or harmful to patients because the research area is beset by 'conceptual, practical and methodological problems' (Churchill et al., 2007, p.7).

In 2013, the OCTET Trial was completed in the UK but found no benefit for CTOs in terms of reduced relapse and readmission to hospital, casting further doubts on their effectiveness (Burns et al., 2013; Rugkåsa et al., 2014b). Subsequent reviews (Maughan

et al., 2014; Rugkåsa et al., 2014a) and a meta-analysis (Kisely and Hall, 2014) further support this view. Taken together, CTOs do not appear to improve clinical outcomes for patients and 'the evidence does not support the use of CTOs in their current form' (Rugkåsa et al., 2014a, p.1861).

Some commentators have questioned the appropriateness of using the number of patients readmitted or days to readmission as outcomes (O'Brien, 2014), arguing that fewer police contacts, reduced victimisation, fewer hospital days, and increased outpatient contacts may be more appropriate indicators of CTO effectiveness (Swartz et al., 2010). Other relevant indicators are social outcomes. Demonstrating, for example, that CTOs improve patient engagement with mental health services, help them find employment, or meet socially with friends, would also be important indicators of treatment success.

Evidence of the effects of CTOs on social outcomes is extremely limited, however. A report emanating from one of the early RCTs conducted in the United States found that patients on CTOs were significantly less likely to be victims of violent crime at one-year follow-up (Hiday et al., 2002). This finding is difficult to interpret however. In particular, the study suffered from high attrition rates (Churchill et al., 2007) and the mechanisms or care pathways that account for the association were not specified (Kisely et al., 2005), making it is difficult to draw conclusions about patients' level of social functioning and their social outcomes more generally. More recently, a secondary analysis from the OCTET Trial reported no significant differences between the trial arms at one-year follow-up in term of symptom severity, global functioning, attitudes to treatment, service engagement, objective social outcomes, and perceived coercion (Rugkåsa et al., 2014b). While relevant to social outcomes, the RCT evidence

to date is affected by a number of general and specific limitations, including the relatively short follow-up duration (12-months of less) and interpretation of the social functioning measures. These limitations are discussed below under the sub-heading *Study rationale and hypotheses*.

1.3.3 Is compulsion harmful?

From a clinical point of view, compulsion is usually justified on the grounds that it will lead to clinical or social benefit for the patient, even if the patient does not recognise this at the time. If a coercive intervention achieves this then the costs to the patient in terms of reduced liberties may be said to be justified. Unfortunately, few studies have directly tested potential harms or unintended consequences resulting from compulsory interventions. Possible indicators of adverse outcome might include a decline in clinical or social functioning, or a patient's subjective experience that the intervention was unhelpful, invasive and unjustified. Høyer (2000) points out that studies that have attempted to assess patients' views of coercion and its negative consequences have mostly been based on the 'Thank you' theory (Stone and Stromberg, 1976), namely that patients retrospectively accept their admissions, or are even grateful, because no harm has been done.

One concern that is repeatedly raised with regards to the use of compulsory interventions is that they may harm the therapeutic alliance and the relationship with health services (Van Dorn et al., 2006). It is easy to see how a compulsory intervention could induce experiences of fear, lack of control, loss of dignity, reduced self-esteem and stigma. Such experiences might alienate patients, cause them to distrust services

and discourage them and others from seeking treatment in the future (Campbell and Schraiber, 1989; Link et al., 2008). However, not all studies have found support for these suppositions. For example, data from the OCTET Trial did not find any differences between the CTO and control group in terms of therapeutic alliance, perceived coercion or satisfaction with treatment (Rugkåsa et al., 2014b). Whether compulsory interventions can actually be said to harm clinical, social or other outcomes – such as self-esteem or the therapeutic alliance – remains unclear and requires further theoretical and empirical attention.

1.4 Outcomes measurement in psychiatry

Outcome assessment is used throughout healthcare to evaluate the effectiveness of interventions or programmes of care. Within mental health research and practice, outcome assessments have historically focused on biomedical endpoints, service utilisation (such as number of readmissions to hospital or contacts with mental health services), and the reduction and control of psychopathological symptoms (Thornicroft and Tansella, 2010; Tulloch et al., 2006). However, it has long been recognised that measuring service use or symptoms alone is not sufficient to capture the breadth of possible outcomes that might be impacted by an illness or an intervention, and information about the patient's social situation is also essential (Juckel and Morosini, 2008; Priebe, 2007).

1.4.1 Social outcomes

Social outcomes can be defined as 'how people live, function in society and perform their various roles' (Priebe, 2007, p.15); they include indicators such as whether a patient is able to work, live independently and have meaningful relationships. Priebe (2007) argues that there are several reasons why social outcomes are particularly relevant in the treatment and management of chronic psychotic illnesses. First, mental health professionals, carers and patient advocacy groups have strongly argued that what really matters for patients is how they actually live – whether they can work, have relationships and live independently – and that social outcomes should consequently be given more prominence in research and clinical practice. Second, psychotic illnesses are frequently chronic, characterised by acute episodes and periods of remission, so capturing the symptoms and associated dysfunction at one point in time may not yield as relevant a picture as the more stable and continuous social situation. Third, longitudinal studies show that psychotropic medications can help control positive symptoms and reduce relapse and readmission to hospital, however, reduced symptoms and rates of relapse alone do not make patients necessarily more likely to find employment, complete education or develop social relationships (Priebe, 2007). Social outcomes therefore need to be assessed separately from symptoms and clinical outcomes.

1.4.2 Measuring social outcomes

A wide range of concepts have been used to reflect and capture social outcomes. These include standard of living, quality of life, social integration, social adaptation, social

functioning, social integration, needs for care and social inclusion (Tulloch et al., 2006; Priebe, 2007). Social outcome measures can be distinguished as either objective or subjective indicators. *Objective indicators* represent objective 'facts' about an individual's social situation, such as having a job or independent accommodation. Priebe (2007) notes that these 'hard' outcomes have the greatest appeal to patients and advocacy groups because an intervention that can be shown, for example, to increase the chances of a patient finding employment or living independently, is more likely to persuade people of its value than instruments or scales that measure symptoms or hypothetical constructs. Although the importance and value of objective indicators is widely recognised, there are several reasons they remain under reported in most studies:

1. Objective aspects of the social situation are 'distal' outcome criteria and therefore difficult to influence and change
2. They suffer from floor and ceiling effects (e.g. if a patient already has independent accommodation then they cannot improve on this outcome)
3. They require value judgements to interpret (e.g. some patients do not wish to work, live independently, or socialise with friends) (Priebe, 2007)

In contrast, *subjective indicators* represent patients' thoughts, feelings and views about their own social situation. These are usually captured through rating scales, checklists and semi-structured interview questions relating to different life domains or life as a whole. Domains that are typically covered include work, family, housing, relationships, safety, finances, leisure and health. The range of available measures to assess subjective indicators is vast. The most commonly assessed subjective outcome

in the psychiatric literature is quality of life (Priebe, 2007). Quality of life measures can be generic, health-related or disease specific. Generic measures are not specific to any one illness and can be used with people with physical and mental health problems and the general population. Because they are non-disease specific, results can be compared between different populations and health conditions. Health-related quality of life measures can also be applied to any health condition but focus on quality of life relating specifically to health. Disease specific measures, in contrast, are designed to measure quality of life in particular conditions, such as schizophrenia. (For a review of the literature, including the most frequently used measures of quality of life in schizophrenia, see Priebe, 2007.)

It is important to remember that mood has been consistently linked with subjectively reported quality of life, with depressed patients consistently reporting poorer quality of life (Kaiser et al., 1997; Newton-Howes, 2014; Priebe et al., 2000). As such, any evaluation of quality of life should control for depression in the statistical analyses.

1.4.3 Social functioning measures for patients with psychotic illnesses

Social functioning is another widely used concept in social outcome studies. Measures of social functioning capture information about an individual's capacity to function in society and meet the obligations of their social roles (Priebe, 2007). Drawing on psychological literature, *social functioning* has been described as 'a global term that reflects a person's ability to interact appropriately and effectively in the social world', a definition that has been used synonymously with *social adjustment* and *social competence* (Hooley, 2010, p.238). The *Handbook of Social Functioning in*

Schizophrenia uses a broader definition of functioning that would include most social outcomes. It defines the breakdown in social functioning characteristic of schizophrenia as 'the inability of individuals to meet societal roles such as homemaker, worker, student, spouse, family member or friend. In addition, individuals' satisfaction with their ability to meet these roles, their ability to care for themselves and the extent of their leisure and recreational activities are often subsumed under the rubric of social functioning' (Mueser and Tarrier, 1998, p.13).

There are a large number of measures designed to assess social functioning in patients with psychotic illnesses most of which focus on schizophrenia. In one review, 301 studies that report social functioning as an outcome in schizophrenia were identified, with 87 different measures used (Burns and Patrick, 2007). Much progress has been made in the assessment of social functioning, but, as with many other social outcomes, there remains a lack of consensus about definitions and measurement (Burns and Patrick, 2007; Figueira and Brissos, 2011).

In summary, social outcomes are widely reported in the psychiatric literature but the development and use of standardised measures that are widely accepted is hampered by conceptual and methodological obstacles (Burns and Patrick, 2007; Priebe, 2007). Many published studies lack clearly defined concepts, use un-validated instruments (or use them inconsistently), or report social outcomes as opportunistic observations rather than as primary outcomes (Burns and Patrick, 2007). The majority of measures 'lack a theoretical model, are not based on universally agreed definitions [and] focus on a limited number of aspects' (Priebe, 2007, pp. 18-19). The predominance of short-term studies in the published literature is a further challenge and there is a need for

long-term studies, particularly those examining treatment effects on social outcomes over time (Hodgson et al., 2007).

1.5 The current study: OCTET Social Outcomes Study

1.5.1 Background: The OCTET Trial

The Oxford Community Treatment Order Evaluation Trial (OCTET) was part of a National Institute of Health Research (NIHR) programme of research on coercion experienced by psychosis patients in England. At the centre of OCTET was a non-blinded parallel-arm RCT, designed to test the clinical effectiveness of CTOs for 'revolving door' patients with psychotic illnesses. Patients (n = 336) were randomised to either CTO or voluntary treatment (Control) and followed up for 12-months. No benefits in terms of reduced relapse and readmission to hospital were found (Burns et al., 2013). There were no significant differences between the trial arms for any of the secondary outcomes including objective social outcomes, global functioning, health-related quality of life, attitudes to treatment, and perceived coercion (Rugkåsa et al., 2014b).

I discussed above that the balance of evidence to date does not support the clinical effectiveness of CTOs. This evidence is based predominantly on three RCTs. One important limitation of these trials is that they have been relatively short (11-12 months) so the longer-term effects of CTOs are uncertain (Rugkåsa et al., 2014a). This is a limitation that applies to both clinical and social outcomes. A further limitation concerns the measurement and reporting of social outcomes. The majority of social

outcomes reported, such as victimisation and global functioning, represent broad approximations of social functioning and are therefore limited in scope. The question of whether CTOs lead to more or less favourable social outcomes for patients across core social domains remains largely untested however (Kisely and Campbell, 2014; Kisely and Hall, 2014). There is consequently a need to assess the longer term effects of CTOs on social outcomes using a comprehensive selection of specifically developed social outcome measures.

The OCTET sample provided a rare opportunity to improve understanding of the relationship between CTOs and long-term social outcomes. A follow-up study – the OCTET Social Outcomes Study – was designed to test this association. A sub-sample from OCTET (n = 121) were interviewed 48-months after entering the trial and assessed via structured research interview on three main social outcomes: social networks (Study 1), social inclusions (Study 2) and patient capabilities (Study 3). A brief introduction to the main concepts and the instruments used, including the rationale for their selection, is described the following section. A more extensive review of literature and theoretical background to these concepts can be found in the introduction to the respective chapters.

1.5.2 Conceptualisation and measurement (Studies 1 to 3)

These studies were designed to test the association between compulsion and long-term social outcomes and a key aim was to capture a breadth of objective and subjective social domains relevant to patients with chronic psychotic illnesses. Instrument selection was determined by a number of factors, including literature

review, discussions with service users, consultation with mental health professionals, and availability of suitable instruments. The rationale for the instruments used in Studies 1 to 3 is described in the following section. Specific instruments are described in detail in the Methods section of the respective studies and reproduced in full in *Appendix I.*

Study 1: Social networks

Social networks have been shown to be an important protective factor for both physical and mental health (Berkman, 1995; House et al., 1988; Kawachi and Berkman, 2001; McNally and Newman, 1999; Uchino, 2004; Umberson and Montez, 2010). Yet numerous studies report that compared to the general population, patients with severe mental illness have smaller social networks, less social support, and are more socially isolated (Albert et al., 1998; Barnett and Gotlib, 1988; Palumbo et al., 2013). Most studies indicate that smaller social networks and poor social support are associated with increased psychological and physical morbidity and mortality (Barnett and Gotlib, 1988; Brugha et al., 1990; McNally and Newman, 1999) and more frequent hospitalisation (Becker et al., 1997; Norman et al., 2005). Among patients with psychotic illnesses, social networks have been observed to be small when compared with the general population and are comprised mainly of family members (Palumbo et al., 2013).

Information about social networks is central to understanding an individual's social situation. The ability to form and maintain social relationships is recognised as a core indicator of social functioning and represents a relatively objective indicator of social

capital, integration, and support. The size and composition of patients' social networks have been used as core indicators of social functioning and outcome in a number of studies (Anderson et al., 1993; Becker et al., 1998; Leff and Trieman, 2000; Palumbo et al., 2013).

The *Social Network Schedule (SNS)* (Dunn et al., 1990) was used to map the size and composition of patients' social networks in Study 1. The SNS was developed in the UK to assess the social networks of patients with severe mental illness (Anderson et al., 1993; Becker et al., 1998; Catty et al., 2005). The instrument captures the number of contacts in the patient's social network with whom the patient had contact in the month preceding interview, relationship type (relative, friend, healthcare professional, etc.), frequency of contact, and whether the contact is considered a confidant. The scale has been previously used in patient samples with psychotic illnesses and is well validated (Becker et al., 1998, Catty et al., 2005; Dunn et al., 1990; Leff and Trieman, 2000).

Study 2: Social inclusion

Patients with severe mental illness are known to be one of the most excluded groups in society (Huxley and Thornicroft, 2003). In recent decades the concept of social inclusion has become increasingly topical in the discourse of healthcare professionals, politicians and policy makers (Baumgartner and Burns, 2014; Morgan et al., 2007; Unit, 2004) and there is a large empirical literature documenting the systematic disadvantage and marginalisation faced by this patient group, including stigma and discrimination, limited social and economic opportunities and freedom of choice

(Morgan et al., 2007; Social Exclusion Unit, 2004). While the concept of *social exclusion* is widely used in the literature, the concept of *social inclusion* is increasingly favoured – possibly reflecting the growing emphasis on improving social participation (Schneider and Bramley, 2008) – and is consequently the preferred concept in Study 2.

Improving social inclusion is recognised as an important treatment and policy aim but there remains a conspicuous lack of reliable and valid measures (Baumgartner and Burns, 2014; Coombs et al., 2013). Two recent reviews of social inclusion measures developed for use in a mental health context found five (Baumgartner and Burns, 2014) and ten (Coombes et al., 2013) measures respectively, though most have undergone quite limited psychometric testing and further validation and testing of all measures is advised. Of the available instruments, both reviews concluded that the Social and Community Opportunities Profile (SCOPE) (Huxley et al., 2012) is the most robust and shows the best potential for further testing (Baumgartner and Burns, 2014; Coombs et al., 2013).

The SCOPE is a self-complete or researcher assisted questionnaire developed in the UK to assess social inclusion in mentally ill populations (Huxley et al., 2012). The instrument contains two sub-scales, *Satisfaction with Opportunities* and *Perceived Opportunities*, as well as objective indicators of social inclusion. The SCOPE was selected to measure social inclusion in Study 2 on the basis that it has good face validity, has undergone the most extensive psychometric testing compared to other instruments, and can be administered relatively quickly (Mezey et al., 2012). The rationale for selecting the SCOPE to measure social inclusion in Study 2 has since been

confirmed by recent reviews of the social inclusion literature (Baumgartner and Burns, 2014; Coombs et al., 2013).

Study 3: Capabilities

Amartya Sen's (1979; 1993; 1999b; 1999a) 'capability' approach has emerged as one of the most influential theoretical contributions to the understanding of human welfare in the last forty years. The capability approach is a normative framework for the evaluation of individual well-being and social arrangements (Robeyns, 2005). Capabilities refer to combinations of functionings – things that an individual has the freedom to *be* or *do* (e.g. being adequately nourished and housed) – which they have reason to value and are able to achieve (Sen, 1993). The approach emphasises freedom of choice, individual difference, and the multi-dimensional nature of human welfare. There is growing interest in the application of the capability approach in mental health contexts where sophisticated, multi-dimensional outcome measures are highly relevant.

Within the mental health context, assessment of disability and health outcomes is currently dominated by utilitarian welfarism, the underlying theoretical approach to quality-adjusted-life-years (QALY) and cost-utility analyses (Lorgelly et al., 2010). The utilitarian approach has been criticised for its failure to capture the breadth of potential life domains that can be impacted by mental illness, and for its limited sensitivity when applied to mental health populations, particularly patients with psychotic disorders and severe and complex non-psychotic disorders (Brazier, 2010). There is increasing agreement among health economists and social scientists that the

capability framework offers the potential for a richer, more nuanced theoretical evaluative space when compared with the standard QALY approach (Francis and Byford, 2011; Lorgelly et al., 2010; Verkerk et al., 2001).

The Oxford Capability Questionnaire for Mental Health (OxCAP-MH) is a multi-dimensional capability instrument developed for use as an outcome measure in mental health research (Simon et al., 2013; Vergunst et al., 2014). The OxCAP-MH was first piloted during the OCTET Trial and was selected as the third social outcome indicator in the OCTET Social Outcomes Study (Study 3). Further work on the psychometric properties of the instrument was also carried out as a secondary objective of this DPhil (Study 5, *Chapter 6*).

In summary, studies 1 to 3 were designed to test the association between psychiatric compulsion and patients' long-term social outcomes. The social outcome measures were carefully selected to cover a range of relevant domains that included both objective and subjective indicators of social functioning, participation and quality of life. The instruments represent distinct conceptual approaches to understanding social outcomes with discrete theoretical and historical backgrounds. The background literature to these approaches is discussed in the introductions to the respective chapters.

1.5.3 Instrument validation (Studies 4 and 5)

Social outcome measurement in mental health research is dependent on the availability of robust measures that are both reliable and valid. As discussed in Section 1.4.1, there are a large number of available social outcome measures although the

majority lack clearly defined concepts, are not based on theoretical models and are poorly validated (Baumgartner and Burns, 2014; Burns and Patrick, 2007; Priebe, 2007). Critical evaluation of existing measures, and validation and testing of promising new instruments, is therefore an important and necessary step in advancing social outcome measurement in mental health research. A further aim of this DPhil was to critically evaluate the SCOPE social inclusion measure, including re-evaluation of its psychometric properties, in a clinical population with psychotic illnesses (Study 4, *Chapter 5*), and to evaluate the psychometric properties of the OxCAP-MH capability measure in terms of internal consistency, test-retest reliability, convergent and discriminant validity, and sensitivity to change in a clinical sample with psychotic illnesses (Study 5, *Chapter 6*).

1.5.4 Study rationale and hypotheses (Studies 1 to 3)

I discussed above that CTOs were introduced on the basis that they would improve patient engagement with services following a period of hospitalisation, increase adherence with treatment, and consequently reduce relapse and subsequent involuntary readmission to hospital (Churchill et al., 2007). Not everyone agrees with this view. Critics have repeatedly argued that CTOs will drive patients away from services, increase the risk of stigma and discrimination, and discourage future help-seeking for fear of further compulsion (e.g. Benthall; Kisely and Campbell, 2014). These views notwithstanding, the balance of evidence to date does not support the clinical effectiveness of CTOs in terms of reduced relapse and readmission.

It is necessary to comment briefly on the nature of the theoretical relationship between the CTO intervention and patients' social outcomes. It is possible that the relationship is a direct one, that is, the CTO influences patients' social outcomes directly, leading to an improvement or deterioration in social outcomes. A second possibility is that the relationship between the CTO and social outcomes is mediated by a third variable, such as clinical functioning (a *mediator*, according to Baron and Kennedy's (1986) widely used definition, is a variable that accounts for (or explains) the relationship between a predictor and a criterion variable). In this case, the relationship between the CTO intervention and a patient's social outcomes is accounted for by their clinical functioning. One implication of the indirect explanation is that improvements in social outcomes may depend to some degree on prior improvement in clinical functioning; in other words, improvements in social outcomes will follow improvements in clinical outcomes. Because the three RCTs found no evidence that CTOs lead to improvements in clinical outcomes, one might conclude that CTOs are unlikely to lead to improvements in social outcomes. This is a possibility but it remains largely untested (Kisely et al., 2014; Kisely and Campbell, 2014).

To date, only two studies have tested the effects of CTOs on a small number of specific social outcomes and both produced mixed results. The first RCT found that compared to voluntary care, patients on CTOs had lower rates of victimisation (Hiday et al., 2002), while the second, a secondary analysis of the OCTET Trial, found that patients on CTOs did no better in terms of objective social outcomes, global functioning, health-related quality of life, attitudes to treatment, and perceived coercion, when compared with voluntary patients (Rugkåsa et al., 2014b). There has been only limited critical discussion and empirical evaluation of CTO effects on social outcomes and

further research has been called for (Kisely et al., 2014; Tulloch et al., 2006). No studies have assessed the relationship between CTOs and social networks, social inclusion or patient capabilities.

As discussed above, a limitation of the three RCTs conducted to date is that they have been relatively short (12-months or less) so the long-term effects of CTOs on patients' clinical and social outcomes remains uncertain. Assessing the long-term effects of CTOs is necessary since many of the mechanisms through which CTOs are thought to operate – such as mobilising support for the patient and improving patient engagement with services and adherence with medication – may take some time to become effective (Churchill et al., 2007; Romans et al., 2004). This is particularly true where social outcomes are used to evaluate the effectiveness of an intervention – such as a CTO – because studies show that social outcomes can take time to change (Priebe, 2007).

In light of the evidence that CTOs do not improve clinical outcomes, no directional hypotheses were made with regards to whether a longer total duration of CTO treatment would be associated with more favourable social outcomes. With respect to hospital compulsion, it has been argued that the main purpose of such treatment is the containment of immediate risk (Holloway and Lloyd, 2011) rather than clinical or social benefits for the patient so no directional hypotheses were made in analyses using this variable as a predictor of social outcomes. Because this follow-up study developed out of an RCT, a further aim was to compare social outcomes based on the original arm of randomisation (CTO vs. Voluntary); however, given the long follow-up duration, and the fact that there was no requirement that the patients were maintained in their arm of randomisation after the first year of the study, any effects

of randomisation could have 'washed out' by 48-months, so no directional hypotheses were made with respect to these outcomes.

Principal and subsidiary questions

The central aim of this DPhil was to test the association between community compulsion (CTOs) and social outcomes: these were the *Principal questions*. Other questions, including the relationship between hospital compulsion (number of days in hospital under legal restriction) and social outcomes, were considered S*ubsidiary questions*. Because any effects of the original OCTET randomisation could have largely disappeared by 48-months, questions relating to differences in social outcomes based on arm of randomisation were also considered subsidiary.

Principal and subsidiary questions were tested for all three social outcomes, namely social network size (Study 1), social inclusion (Study 2) and capabilities (Study 3). In all principal analyses, the total number of days of CTO treatment during follow-up was used as the main predictor. Since only patients who are living in the community can be subject to CTOs, and any treatment effects are likely to occur there, a further sensitivity analysis was conducted in which the main predictor (number of days on a CTO) was calculated as a proportion of days spent in the community during follow-up. In addition to the principal and subsidiary questions listed below, several additional questions relevant to the particular studies and the instruments used were also included, and these are listed under the subsidiary questions in the respective chapters.

1.6 Research questions

Principal questions (Studies 1 to 3)

1. Is a longer duration of CTO treatment over 48-months associated with more or less favourable social outcomes at follow-up?
2. Is a longer duration of CTO treatment over 48-months, calculated as a *proportion* of time spent in the community, associated with more or less favourable social outcomes at follow-up?

Subsidiary questions (Studies 1 to 3)

1. Is a longer duration of involuntary hospitalisation over 48-month associated with more or less favourable social outcomes at follow-up?
2. Is a longer duration of *any* compulsion (hospital and community) over 48-months associated with more or less favourable social outcomes at follow-up?
3. Are there between-group differences in social outcomes in the randomised groups (CTO vs Control)?
4. Is gender (Male vs. Female), age (<40 years vs. ≥40 years) or ethnicity (White vs. Other) associated with more or less favourable social outcomes?

Critical evaluation of the SCOPE social inclusion measure (Study 4)

1. Is the SCOPE a feasible, reliable and valid measure of social inclusion in a clinical research context with patients with psychotic illnesses?

Psychometric evaluation of the OxCAP-MH capability measure (Study 5)

1. What are the psychometric properties of the OxCAP-MH capability instrument (internal consistency, test-retest reliability, convergent and discriminant validity and sensitivity to change) in a clinical sample with psychotic illnesses?

Chapter 2 Social networks and psychiatric compulsion

If you can't find peace, find some friends for the war

– Thomas Hobbes

2.1 Introduction

2.1.1 Background

Human beings are highly social creatures who develop and maintain complex networks of social relationships across the life course. The importance of these bonds for health and well-being has been recognised since ancient times but they were not systematically studied until the 19th Century. The study of social networks has its origins in sociology and social anthropology, going back at least as far as Durkheim (Durkheim, 1951 [1897]) and has since become a highly interdisciplinary field with important applications in sociology, psychology, psychiatry, statistics and mathematics. Although psychologists such as Jacob Moreno began to systematically record and analyse social interactions in small groups in the 1930s, the concept was not introduced into mental health research until the 1950s (e.g. Barnes, 1954). There is now a well-established literature documenting the social networks of individuals

with mental illness in which a large variety of descriptions and definitions of the concept of social networks can be found.

Bott (1957), an early pioneer in the field, defined the social network as 'all or some of the social units (individuals or groups) with whom a particular individual or group is in contact' (p.320). Mitchell (1969) described it as '…a specific set of linkages among a defined set of persons, with the additional property that the characteristics of these linkages as a whole may be used to interpret the social behaviour of the persons involved' (p.2). More recently, Umberson and Montez (2010) have described social networks succinctly as '…the web of social relationships surrounding an individual, in particular, structural features, such as the relationship type and strength of each social relationship' (p.1). The term *social ties* is widely used in the literature and refers to the bonds that make up social networks. *Social support* refers to the support (psychological, physical, practical, etc.) that flows through social ties. These terms can be contrasted with *social isolation* which refers to a relative absence of social ties and support (Smith and Christakis, 2008).

2.1.2 Social ties and health

Social ties and support have long been associated with better physical and mental health outcomes across the life course (Smith and Christakis 2008). In contrast, social isolation has been consistently linked with wide range of negative health outcomes (Berkman et al., 1995; Uchino 2004). For example, prospective studies from the general population show that mortality rates from nearly all diseases are inversely associated with the number of social contacts in individuals' social networks, even

after controlling for confounding factors such as health behaviours and socio-economic status (House et al., 1988; McNally and Newman, 1999; Umberson and Montez, 2010). Review articles consistently report that individuals with a lower quantity and quality of social relationships are more likely to experience a range of physical health conditions such as hypertension, cardiovascular disease, cancer, slower wound healing, and even the common cold (Cohen et al., 1997; Ertel et al., 2009; Everson-Rose and Lewis, 2005; Uchino, 2006). Studies on marriage – one of the most frequently studied social relationships – have shown again and again that marital history influences a wide range of short and long-term health outcomes (Hughes and Waite, 2009; Robles and Kiecolt-Glaser, 2003; Zhang and Hayward, 2006).

Compared to the number of studies that have examined effects of social support on physical health outcomes, relatively few have tested the effects on mental health outcomes. Nevertheless, a link between smaller social networks and poorer mental health has been reported across a range of clinical populations (Greenblatt et al., 1982; Kawachi and Berkman, 2001). In particular, smaller social networks and lower levels of social support have been linked with increased depressive symptoms and worse clinical outcomes (Barnett and Gotlib, 1988; Brugha et al., 1990) and increased risk of onset (and subsequent relapse) of psychosis (Boydell et al., 2004; Broome et al., 2005; Reininghaus et al., 2008). Among patients with psychotic illnesses, smaller social networks have been linked with poorer functional status (Howard et al., 2000) and increased risk of hospitalisation (Becker et al., 1997; Norman et al., 2005).

2.1.3 Social networks and psychosis

The social networks of people with schizophrenia and other psychotic illnesses have been the subject of a number of studies which show that they have on average smaller social networks with higher concentrations of family members when compared with the general population (Macdonald et al., 2000; Palumbo et al., 2013). A recent systematic review reported that patients had a mean of 12 contacts in their social networks compared to figures of 25 (Pattison et al., 1975) and 40 (Cresswell et al., 1992) reported for the general population. Compared with patients with common mental disorders (e.g. depression, anxiety), patients with psychotic illnesses are less likely to find social contacts outside of those provided by staff in mental health services (Beels, 1981; Buchanan, 1995) and to find their social contacts less helpful and less supportive (Becker et al., 1997). Social network size has been shown to be positively correlated with subjective quality of life for patients with psychotic illnesses (Becker et al., 1998; Hansson et al., 2002), while smaller social networks have been linked to poor psychosocial outcomes including reduced self-esteem, low social confidence, and poorer communication skills (Harley et al., 2012).

2.1.4 Social networks and illness: cause or consequence?

There has been much discussion about whether the smaller social networks commonly observed among people with severe mental illness are a cause or consequence of the illness. Establishing a causal relationship between social ties and mental health outcomes is methodologically challenging however (Kawachi and Burkman, 2001). A major difficulty is recall bias including the degree to which patients

who are unwell can reliably recall the details of their social network. Few studies have access to reliable data prior to the onset of illness. Even with longitudinal studies it can be very difficult to establish whether reduced social ties are an antecedent or consequence of the mental illness (Kawachi and Burkman, 2001). In depression, for example, it is possible that certain personality traits such as introversion and (dis)agreeableness are associated both with lower levels of social participation and the occurrence of depressive symptoms. A recent review suggests that the smaller social networks of patients with psychotic illnesses may be both a cause and consequence of the illness, though smaller networks appear to predate the onset of illness (Gayer-Anderson and Morgan, 2013). Causality notwithstanding, there is general consensus that social ties have an important protective effect on mental health and psychological well-being (Kawachi and Berkman, 2001; Barnett and Gotlib, 1988). If social ties have such a potent effect on health, through which mechanism or set of mechanisms are they believed to operate?

2.1.5 Mechanisms

Converging literature from a range of disciplines suggests that behavioural, physiological and psychosocial mechanisms underlie the relationship between social ties and both physical and mental health (Berkman, 1995; Cohen and Janicki-Deverts, 2009; Thoits, 2011; Uchino, 2006; Umberson and Montez, 2010). Some suggested mechanisms include (1) the provisions of social support (both perceived and actual), (2) social influence (e.g., norms, social control), (3) social engagement, (4) person-to-person contacts (e.g., pathogen exposure, passive exposure to tobacco smoke), and (5) access to resources (e.g., money, jobs, information) (Berkman and Glass 2000).

Although all mechanisms are linked and understood to interact in complex ways which influence health cumulatively, psychosocial mechanisms are generally thought to be the most important pathway through which social ties might influence mental health.

There is general consensus that social ties and the support derived from them act positively and causally to shape physical and mental health outcomes (Ertel et al., 2008; Thoits, 2011; Uchino, 2006). The relationship between social ties and mental health operates through direct and indirect pathways. For example, psychosocial mechanisms such as social support can act indirectly by increasing perceived support, feelings of mattering, self-esteem and self-efficacy, which can buffer against the negative effects of stress and trauma, although this relationship has been less consistently documented than the direct effects of social ties on health (Kessler et al., 1985; Thoits, 1995; Thoits, 2011). The nature of this indirect relationship can be described as a mediated association where a variable such as self-esteem explains or accounts for the association between social ties and mental health (Baron and Kennedy, 1986).

A number of studies have tested the association between social ties and support and early psychosis but questions about the factors that mediate or moderate the association remain (Gayer-Anderson and Morgan, 2013). In a recent review of the literature, Gayer-Anderson and Morgan (2013) note that most studies focus on one of three main aspects of social networks and support that may impact on resilience and alter the threshold for the onset of illness: (1) perceptions of social support – that is, a subjective belief that one is valued by others and that one can turn to others for support when needed, (2) the actual provision of support (e.g. emotional or practical),

and (3) the structure of social networks (e.g. number, frequency, and quality of social interactions). This latter aspect is the most frequently documented and is typically used as a proxy for social integration, social capital and support, on the assumption that having more contacts is beneficial (Beels, 1981).

2.1.6 Measuring social networks

There is large variation in the conceptualisation and measurement of the social networks of people with psychotic illnesses (Palumbo et al., 2013). Some researchers have employed narrow definitions that include only friends and/or family ties (Strauss and Carpenter, 1972) while others favour broader definitions that also include neighbours and other close associates (Budson and Jolley, 1978). Instruments used to assess social networks range from the basic (e.g. counting the number of friends) to sophisticated in-depth interviews (Turner and Brown, 2010). The most frequently studied features of social networks among patients with psychotic illnesses have been described in a recent systematic review by Palumbo and colleagues (2013). These features are outlined below.

The *number of social contacts* is by far the most widely reported feature of patients' social networks. Depending on the definition used, social contacts can include friends, relatives, acquaintances, colleagues, and so on, and are usually reported as a mean or median score of the total number of contacts. A time frame within which the contact was seen or contacted is sometimes given, for example, within the past four weeks.

Frequency of social contact is also commonly reported, such as if a contact is seen daily, weekly, fortnightly, etc. Most studies also report the *Relationship type*, for

example, relative, friend, acquaintance, health professional, etc., and the usual location of contact (e.g. home, healthcare setting).

More sophisticated designs have attempted to assess the *density* of social networks. Density has been defined as the proportion of linkages between network members when all potential linkages are considered (Horan et al., 2006). It is used as an estimate of the numerical strength of interpersonal ties within the network (Famuyiwa and Olatokunbo, 1984).

The *degree* of contact refers to the average number linkages each person has with the others in the same network (Cohen and Sokolovsky, 1978; Lipton et al., 1981). Degree is calculated using a different formula to that used to calculate density; the formula corrects for the tendency of larger networks to result in lower densities due to the greater number of ties that need to be generated in order to maintain high density (Palumbo et al., 2013).

Intensity, also referred to as 'plexity', has been used to identify contacts' degree of involvement in the life of the patient, distinguishing individuals who are involved in only one life domain or context from those involved in several. Uniplex or single-stranded relationships have one contact area (e.g. practical support, lending, casual conversations) while multiplex relationships cover several areas. Multiplex relationships are potentially more beneficial to the patient, are therefore relevant to social network research (Tolsdorf, 1976), but are also more difficult to assess.

The *directionality* of relationships has also been investigated by a number of studies. Directionality attempts to establish the direction in which support flows in a dyadic relationship. For example, relationships can be instrumental (patient is primary

recipient of support etc.), reciprocal, or dependent (patient is primary provider) (Cohen and Sokolovsky, 1978).

The *Intimacy* of relationships has been variably defined, but usually refers to the degree of emotional closeness and whether the contact is considered a confidant. Some studies also record the *type of contact* which can be face-to-face, telephone, letter, email, text messaging, or social networking sites and online 'chatrooms'. To date, few studies have included social contacts through the internet, partly because the technology is relatively new and methods to capture these interactions are still being developed.

In summary, there is considerable heterogeneity among clinicians and researchers about which features of social networks are most relevant as outcomes for patients with psychotic illness. While most features of patients' social networks can be descriptively reportedly, studies often require the selection of one or more features for use in hypothesis testing, and deciding on which ones are most relevant can be challenging. The total number of contacts is the social network feature that is most widely reported in the literature on the basis that it represents an approximation for overall social functioning and support (Palumbo et al., 2013). This feature was used as the main outcome in all analyses in Study 1.

2.1.7 Improving social networks

Given that social networks are closely linked with both physical and mental illness, and that patients with psychotic illnesses are known to have smaller social networks than the general population, there is a strong case for improving social networks and

social support for this group (Becker et al., 1998; Frick et al., 2013; Palumbo et al., 2013; Sündermann et al., 2014). Interventions that improve social networks and support should be developed and tested, while the effects of social policy changes and other legal or social interventions (such as community compulsion) that directly or indirectly impact on social networks and support should also be evaluated. The effects of community compulsion on social networks and support have not been assessed in any published study to date.

2.1.8 Psychiatric compulsion and social networks (Study 1)

The use of non-consensual treatment has generated considerable debate both inside and outside the discipline of psychiatry (sees *Chapter 1*). Although the use of compulsion was historically restricted to circumscribed hospital settings, the legal authority of the psychiatric profession has been expanded in many countries to include compulsory community interventions (community treatment orders; CTO). A lack of convincing evidence for either the harms or benefits of CTOs has driven much of the debate though the evidence to date does not appear to support their use (Maughan et al., 2013; Rugkåsa et al., 2014a). The majority of trials testing CTO effectiveness have been short (11 to 12 months) and focused almost exclusively on clinical outcomes (readmission to hospital) (Kisely et al., 2014; Tulloch et al., 2006). There has been only limited critical discussion and empirical evaluation of CTO effects on social outcomes and no studies have tested the potential benefit or harm to patients' social networks, particularly in the long-term. To address this, we designed a follow-up study to test whether the duration of the CTO intervention was associated with larger or smaller social networks. A sub-sample from the OCTET Trial was

followed up 48-months after randomisation and assessed by research interview, which included measures of patients' social networks, and clinical and social functioning.

A detailed description of the rationale for the study including justifications for directional hypotheses can be found in the introductory chapter under the heading *Study rationale,* Section 1.5.4.

2.2 Research questions

Principal questions

1. Is a longer duration of CTO treatment over 48-months associated with a larger or smaller social network at follow-up?
2. Is a longer duration of CTO treatment over 48-months, calculated as a *proportion* of time spent in the community, associated with a larger or smaller social network at follow-up?

Subsidiary questions

1. Is a longer duration of *involuntary hospitalisation* over 48-months associated with a larger or smaller number of total contacts in patients' social networks at follow-up?
2. Is a longer duration of *any* compulsion (hospital and community) over 48-months associated with a larger or smaller number of total contacts in patients' social network?

3. Do patients who were randomised to the CTO arm have larger or smaller social networks than patients in the Control arm?
4. Is gender (Male vs. Female), age (<40 years vs. ≥40 years) or ethnicity (White vs. Other) associated with the number social contacts in patients' social networks?
5. Is illness severity and overall functioning associated with social network size?

2.3 Methods

2.3.1 Sample

The OCTET Trial

Patients in the OCTET Trial were recruited and randomised between November 2008 and February 2011 (Burns et al., 2013). Inclusion criteria were: aged 18-65 years, primary diagnosis of psychotic illness, currently detained for inpatient treatment under the Mental Health Act, considered suitable for a CTO, and able to give informed consent. Patients with insufficient English were not interviewed because the instruments had not been validated in other languages although socio-demographic and clinical data were collected for them from medical records. Patients were identified by psychiatrists in participating Community Mental Health Teams (CMHT). Following recruitment, patients were randomised to either CTO or voluntary treatment (Control group) and interviewed at baseline, 6-months and 12-months. Socio-demographic data, admission history and changes in legal status were collected from medical

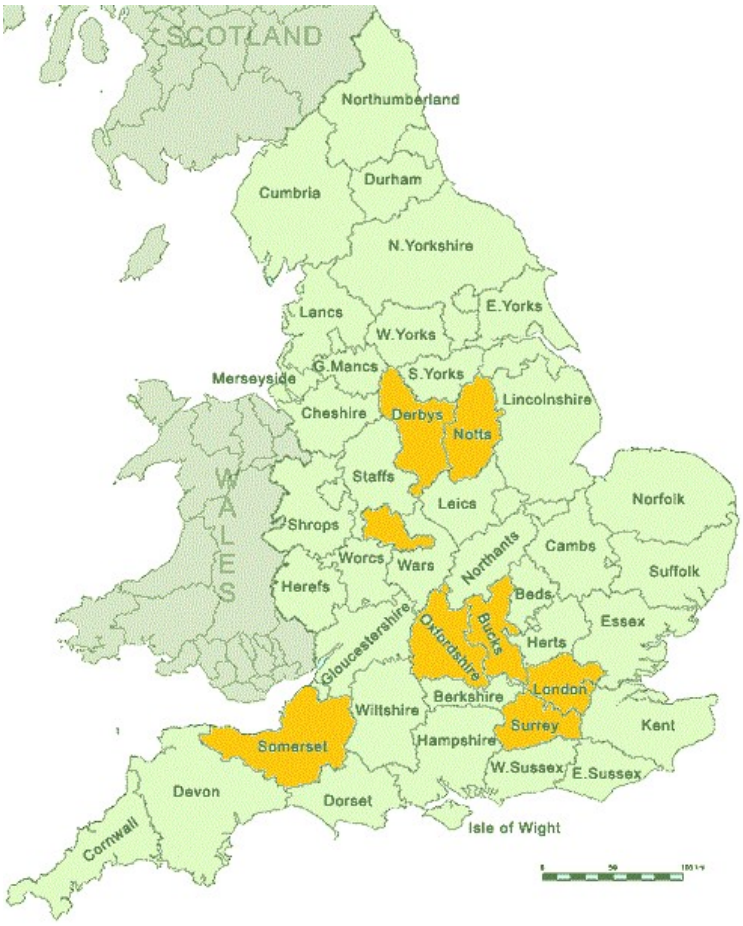
records at hospitals or community mental health teams. A subsequent study – the OCTET Follow-up Study – was conducted to test whether CTO use was associated with disengagement from services and readmission to hospital 36-months after randomisation (Burns et al., in press). All data for this study were collected from patients' medical records.

The study was carried out in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki and its later amendments (World Medical Association, 2013). Ethical approval was granted by the regional NHS authority [REC ref. 08/H1204/131] and all patients gave informed consent prior to participation.

OCTET Social Outcomes Study

A sub-sample of 210 patients who reached their 48-month follow-up date between January 2013 and December 2014 were identified for follow-up across 14 NHS Trusts that were geographically accessible from Oxford (Avon and Wiltshire; Barnet, Enfield and Haringey; Birmingham and Solihull; Camden and Islington; Central and North West London; Derbyshire; East London; Nottinghamshire; North East London; Oxford; South London and Maudsley; South West London and St Georges; Surrey and Borders; West London) (**Figure 2**). A modification and extension to the original ethical approval for the OCTET Social Outcomes Study was sought and granted in November 2013 [REC ref. 08/H1204/131].

Figure 2 Geographical locations of participating NHS Trusts (n = 14) in the OCTET Social Outcomes Study



2.3.2 Power calculation

A power calculation for this study was considered but, due to the limited published literature on CTO effectiveness and the difficulty of estimating 'meaningful change' in patients' social network size, would have been highly speculative and consequently of little value. A post hoc power calculation was also considered, but again this was considered of limited value given that no significant associations were found in the regression analyses and all effects sizes were small.

2.3.3 Design and procedure

The OCTET Social Outcomes Study had a prospective observational design. Patient data were collected via structured research interview, which I conducted myself, using the instruments described in below (Section 2.3.3). I contacted patients via their care coordinator or clinician or, where they had been discharged from mental health services, directly via letter or telephone. Initially both inpatients and out patients were considered for interview, but this was later amended to include only patients resident in the community for the past four-weeks (social outcomes measures used in the study were not considered relevant to an inpatient context). Patients were seen within a 'window period' of 16-weeks on either side of their 48-month follow-up date. Interviews lasted approximately one-hour and patients were reimbursed with £25 for their time. All patients gave informed consent in writing prior to interview.

Socio-demographic and clinical details (including changes in legal status and hospital admissions) for the first 36-months were collected from medical records (located at

psychiatric hospitals and community mental health teams) as part of the OCTET Follow-up Study by myself and a team of research assistants (CA, AF, SP, LR and LT; see acknowledgements). I collected all relevant data for changes in legal status and hospital admissions for the 4th year of follow-up in the same way.

2.3.4 Instruments used in the study

The following instruments were used in the study. A copy of the Patient Interview Booklet containing all instruments used in the OCTET Social Outcomes Study can be found in *Appendix I*.

Social networks: *The Social Network Schedule (SNS)* (Dunn et al., 1990) is a researcher-rated instrument used to describe the number, frequency, location, relationship type, and intimacy of social contacts in the last month as well as the total number of contacts in the patient's social network. Patients are asked to list all social interactions (e.g. face-to-face conversations, telephone calls, letters, emails, online social networking) that they have had in the last month with people whom they would consider part of their social network. Contacts are then categorised according to relationship designation (hospital staff, community staff, hospital patient, community patient, relative, friend/acquaintance, neighbour, workmate or 'other') and where they are usually seen (home, healthcare setting, anywhere else). Patients are asked whether the contact is a friend or an acquaintance, whether they would miss the contact if they were no longer able to see them, and whether that contact is a confidant ('Do you talk to X about personal feelings or worries?'). No formal definition of 'contact' is given other than 'someone you would consider part of your social

network'; social contacts must be people they have at least spoken to rather than 'just saying hello' (Catty et al., 2005). Patients use their own definitions of 'friendship'. The SNS has been used in a number of studies with patients with psychotic illnesses and is well validated (Dunn et al., 1990). Data are reported descriptively.

Health-related quality of life: *EuroQol EQ-5D* (EuroQol-Group, 1990; Glick, 1999) is a self-complete questionnaire that assesses health-related quality of life at the time of interview. The instrument has two components. The EQ-5D-3L is a five dimension health-related quality of life questionnaire (Mobility, Self-Care, Usual Activities, Pain and Discomfort, and Anxiety/Depression) with three levels for each dimension (not present = 1, moderate disability = 2, severe disability = 3). Scores for the 3L can be converted to standardised 'utilities' based on UK population norms, ranging from 1 (11111) to -0.59 (33333), with 1 being the equivalent of perfect health and zero the equivalent of dead. The EQ Visual Analogue Scale (EQ VAS) is a 0 to 100 measure of current health status where 0 and 100 represent the worst and best imaginable health states respectively. The EQ-5D is a generic, multi-attribute instrument widely used in health economics research as the main outcome measure for cost utility analyses. Reference to the EQ-5D in this study is to the 3 level (3L) version throughout.

Psychopathology: *The Brief Psychiatric Rating Scale (BPRS)* (Mortimer, 2007; Overall and Gorham, 1962) is a clinician-rated measure of psychiatric symptom severity based on the two weeks prior to interview. The instrument has 24 items that are rated on a seven point scale from not present (1) to extremely severe (7). It has a minimum score of 24 and maximum of 168, with higher scores indicating greater symptoms severity and poorer functioning.

Global functioning: *The Global Assessment of Functioning (GAF)* (Hall, 1995) is a clinician or researcher rated measure of overall functioning. It combines symptoms and social/occupational functioning into a single score from 0 to 100 with higher scores indicating superior functioning.

Objective social outcomes: *The Objective Social Outcomes Index (SIX)* (Priebe et al., 2008) is a brief index used for benchmarking social outcomes by capturing objective information about an individual's social situation in four domains: employment (0 = none, 1 = voluntary/protected/sheltered, 2 = regular), living situation (0 = homeless, 1 = sheltered / supported, 2 = independent), partnership / family (0 = living alone, 1 = living with partner / family), and social contact in the last week (0 = not met a friend in the past week, 1 = met a friend in the past week). The instrument scores from 0 to 6 with higher scores indicating better outcomes.

Perceived coercion: *Admission Experience Survey (AES)*, adapted for out-patient use (Swartz et al., 2002), is a 15-item self-complete or clinician-assisted measure which asks patients to rate statements on a 5 point Likert scale (1 = strongly agree, 5 = strongly disagree). The AES contains three sub-scales, of which the five-item Perceived Coercion Scale (AES-PC) was used in this study. The AES-PC asks about patients' perception of influence and control in treatment decisions over the past six months. Scores range from 5 to 25 with higher scores indicating greater perceived coercion.

2.3.5 *Data management*

After completing each interview, I scored the instruments and entered the data into a database (SPSS). After all interviews had been completed, I checked a random sample of 22 participants (20%) for errors by re-entering the data into a second database and comparing the first and second entry for accuracy. I also checked the complete dataset for errors using range checks and logical and consistency checks.

Data for changes in legal status and psychiatric hospitalisations were entered directly into a custom built Access database by researchers (CA, AF, SP and myself). The first 66 patient records were collected on paper and subsequently entered into an Excel database. For these cases, all data were double entered by two different researchers (AM and KB), compared for accuracy, and then corrected. Once entered, these data were checked for errors using range checks and logical and consistency checks. 'Raw' compulsion data (dates of legal status change and hospital admission/discharge) were then exported into an Excel database where the days under compulsion and days in hospital were calculated for all patients before being imported to the SPSS database for analysis.

2.3.6 *Statistical analyses*

Data were checked for normality using the one-sample Kolmogorov-Smirnov test of goodness of fit. Descriptive statistics in this study used means (SD) for normally distributed data, medians (IQR) for non-normally distributed data, and number (%) for categorical data. Between-group comparisons used t-tests for normally distributed

data, Mann-Whitney U tests for non-normal data and Chi square tests for categorical data. Effect sizes (*r*) for Mann-Whitney U tests were calculated by dividing Z scores by the square root of N ($r = Z/\sqrt{N}$). Alpha was set at .05 and all significance tests were two-tailed. All data were analysed using the Statistical Packages for the Social Sciences (SPSS) version 20 (SPSS, 2011).

Duration of compulsion

The duration of compulsion between randomisation and 48-months follow-up was calculated as follows: community compulsion was the total number of days spent on a CTO (Section 17a); duration of involuntary hospitalisation was the total number days on any other Section (e.g. Section 2, 3, 4, 136, 37, 40/48) including the index admission for the period after randomisation; total compulsion was defined as the sum of the number of days of CTO treatment and the number of days of involuntary hospitalisation. Total days of CTO treatment as a proportion of days spent in the community during 48-month follow-up was calculated as follows: CTO/(VOL+CTO)×(VOL+ALL) where CTO is the total days of CTO treatment; VOL is the total days voluntary; and ALL is total days of any compulsion (CTO and hospital). For ease of interpretation, the number of days of CTO treatment (community compulsion) and number of days of involuntary hospitalisation (hospital compulsion) were converted into months by dividing the total number of days by 30.43 prior to analysis. This reduced the number of decimal places in the beta coefficients making the ratio between the predictor and outcome larger and therefore easier to interpret.

Principal analyses

Negative binomial regression was used to test for an association between the duration of compulsion and social network size. This analysis is considered most appropriate for count outcomes (e.g. number of social network contacts) where the variance of the outcome is also larger than the mean, as in the present study. The total number of contacts in the social network was entered as the outcome and the number of months of community compulsion as the main predictor. These were initially analysed alone to test the model assumptions before controlling for: age, gender, duration of illness, diagnosis (schizophrenia vs. other), illness severity (total days in hospital during follow-up) and perceived coercion at 48-month follow-up. This analysis was repeated for the second principal question using the total number of months of CTO treatment calculated as proportion of months spent in the community as the main predictor. Results for this model are presented as Incident Rate Ratios (IRR) with 95% confidence intervals (CI). An IRR is interpreted as an increased or decreased incidence (rate) of an outcome at a given time point, where 1 represents no change.

Subsidiary analyses

The negative binomial regression model used for the principal analysis above was also applied to questions 1 and 2 in the subsidiary analyses by replacing the main predictors with the *total number of days of involuntary hospitalisation* and *total number of days of any compulsion* in the respective analyses. A between-groups analysis using randomisation as the grouping variable was conducted for the total number of contacts and all subsidiary sections of the SNS.

The association between the total number of social contacts (and the number of confidants) and indicators of illness severity (BPRS) and global functioning (GAF) was explored using Spearman correlations and scatter plots.

All aspects of the social network captured by the SNS were explored by gender, age (<40 years vs. ≥40 years) and ethnicity (White vs. Other) and significant differences assessed using Mann-Whitney U tests. For 'Other' ethnicity, Asian, Black British, Mixed race, and 'Other ethnic group' were collapsed into a single category.

2.4 Results

2.4.1 Participant flow and follow-up

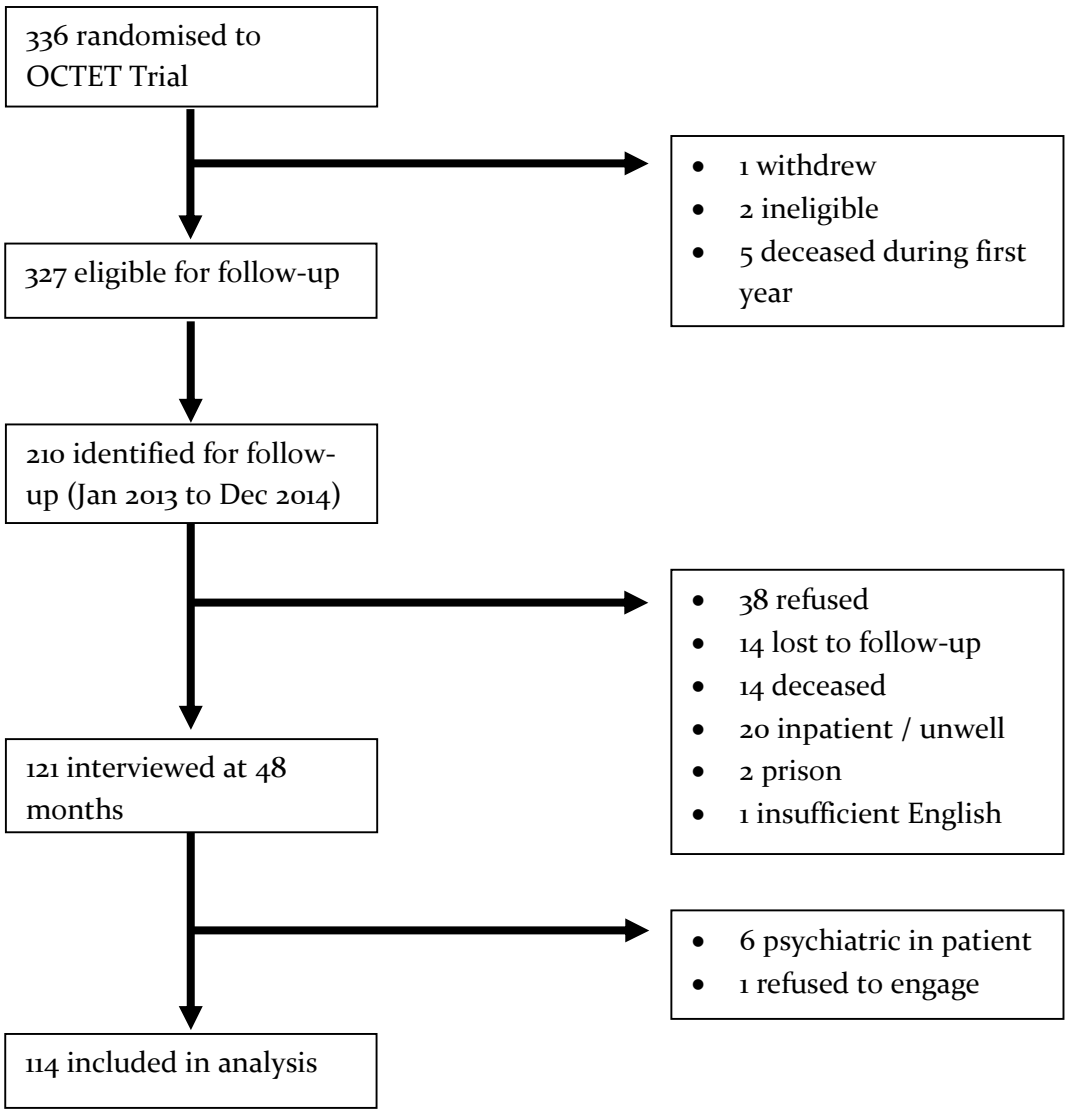
Of the 336 patients randomised to the OCTET RCT, three were excluded (one withdrew and two were found to be ineligible) leaving 333 in the analysis. From this sample, 210 patients were identified for follow-up on the basis that they were under the care of NHS Trusts (n = 14) that were geographically accessible from Oxford and that they were due to reach their 48-month follow-up date between January 2013 and December 2014 (**Figure 3**). Of these, 121 patients were interviewed at 48-months. Of the remaining patients identified for follow-up, 38 (18%) refused, 14 (7%) were lost to follow-up (two had moved abroad), 14 (7%) were deceased, 20 (10%) were psychiatric inpatients and/or too unwell (based on the opinion of the patient's care coordinator or, if seen for the interview, were unable to understand the purpose of the interview), 2 (1%) were in prison, and 1 (<1%) did not speak English. Of the patients who were interviewed, 6 (3%) were excluded because they were currently detained in hospital

(the study questions are predominantly concerned with outcomes in the community), and 1 (<1%) was excluded because she refused to answer the interview questions, leaving 114 in the study. All analyses were conducted on this sample. One participant in the study listed film stars and other celebrities among their social contacts, who were believed to be fictitious/delusional; following confirmation of this from staff at the patient's supported accommodation, these contacts (n = 6) were removed from the database.

The socio-demographic and clinical characteristics of the full sample (n = 336), patients identified for follow-up (n = 210), and patients actually seen and included in the analysis (n = 114), did not significantly differ except in terms of ethnic composition: there were significantly fewer White British participants in the sample identified for follow-up (47%), and in the sample followed up (49%), when compared with the original sample (61%) ($p < 0.05$) **(Table 1)**.

Cases that did not have complete data for the outcome and all predictors were dropped from the regression analyses. Thus, of the 114 eligible patients, nine were removed because of missing data for the AES-PC (the AES-PC was used to control for perceived coercion at follow-up but could not be completed by patients who had been discharged from mental health services since the instrument asks about experiences of pressure/coercion in relation to the patient's care coordinator and CMHT in the last six months). One further patient was dropped because their duration of illness was unknown. All regression analyses were consequently conducted on a sample of 104 patients.

Figure 3 Participant flow for the OCTET Social Outcomes Study



2.4.2 OCTET Social Outcomes Study baseline characteristics

Of the 114 patients included in the final analysis, 76 (67%) were male, 56 (49%) were White British, 37 (33%) were Black, 15 (13%) were Asian, and 6 (5%) were 'Mixed/Other'. The majority of patients (86, 75%) were born in the UK and were

unemployed (99%). Patients had a mean of 12 years of education. Only 11 patients (10%) were married or cohabiting, though the majority were living independently (87, 76%). Patients had a mean age of 40 years and had been unwell for almost 15 years. The majority of patients had a diagnosis of schizophrenia, schizotypal or delusional disorder (94, 83%), while 20 (17%) had diagnoses of other psychotic illnesses including bipolar disorder. Socio-demographic and clinical characteristics of the sample are presented in **Table 1**

Table 1 Baseline socio-demographic and clinical characteristics for OCTET Trial and Social Outcomes Study

	OCTET Trial				OCTET Social Outcomes Study			
	Missing data		Randomised		Eligible		Interviewed	
	n = 336		n = 336		n = 210		n = 114	
	N	(%)	N, Mean or Median	(%), (SD) or (IQR)	N, Mean or Median	(%), (SD) or (IQR)	N, Mean or Median	(%), (SD) or (IQR)
Demographics								
Age	0	(0%)	39.7	(11.4)	40.2	(11.5)	39.5	(11.1)
Sex	0	(0%)						
Male			225	(67%)	137	(65%)	76	(67%)
Female			111	(33%)	73	(35%)	38	(33%)
Years of education	4	(1%)	11.9	(1.9)	12.0	(1.9)	11.8	(1.7)
Ethnic origin	0	(0%)						
White British			204	(61%)*	99	(47%)	56	(49%)*
Black			77	(23%)	71	(34%)	37	(33%)
Asian			29	(9%)	24	(11%)	15	(13%)
Mixed and Other			23	(7%)	16	(8%)	6	(5%)
Born in the UK	1	(<1%)	259	(77%)	149	(71%)	86	(75%)
Employment and living situation								
Regular part- or full-time employment	1	(<1%)	2	(<1%)	2	(1%)	7	(6%)
Married/co-habiting	2	(<1%)	29	(9%)	19	(9%)	11	(10%)

	OCTET Trial				OCTET Social Outcomes Study			
	Missing data		Randomised		Eligible		Interviewed	
	n = 336		n = 336		n = 210		n = 114	
	N	(%)	N, Mean or Median	(%), (SD) or (IQR)	N, Mean or Median	(%), (SD) or (IQR)	N, Mean or Median	(%), (SD) or (IQR)
Independent accommodation	2	(<1%)	241	(73%)	154	(74%)	87	(76%)
Living alone/homeless	18	(5%)	148	(44%)	93	(44%)	53	(47%)
Clinical status								
Schizophrenia	0	(0%)	286	(85%)	180	(86%)	94	(83%)
Brief Psychiatric Rating Scale	22	(7%)	38.8	(11.1)	38	(11.4)	38.3	(12.1)
Global Assessment of Functioning	25	(7%)	38.9	(9.8)	39	(9.6)	38.4	(9.7)
Clinical history								
Duration of illness (years)	9	(3%)	14.4	(10.4)	14.5	(10.6)	14.3	(10.8)
No. of past psychiatric hospital admissions	22	(7%)	5	[3-9]	5	[3-8]	5	[3-9]
No. of months of past psychiatric hospitalisation	58	(17%)	15	[7-30]	14	[6-30]	14	[6-30]
No. of past involuntary hospital admissions	33	(10%)	4	[2-7]	4	[2-7]	4	[2-7]

** Significant at the 0.05 level; NOTE: percentages may not sum to 100 due to rounding*

2.4.3 Interventions during follow-up

Interventions and changes in legal status during the 48-month follow-up are presented in **Table 2**. Following randomisation, 103 patients (90%) spent at least one night in hospital (including the index admission), a mean of 5.8 (SD = 7.3) months in hospital during follow-up. Altogether, 55 patients (48%) were readmitted to hospital at least once, with a median of 1.0 (range 0 – 11) admissions.

Table 2 Interventions and changes in legal status during 48-month follow-up

	Total sample				**CTO arm**				**Control arm**			
	n = 114				**n = 57**				**n = 57**			
	N or Mean	**(%) (SD)**	**Median**	**[IQR]**	**N or Mean**	**(%) (SD)**	**Median**	**[IQR]**	**N or Mean**	**(%) (SD)**	**Median**	**[IQR]**
No. of patients readmitted	55	(48%)	-	-	30	(53%)	-	-	25	(44%)	-	-
No. of readmissions	1.0	(1.7)	0	[0-1]	1.3	(2.1)	1	[0-2]	0.8	(1.1)	0	[0-1]
No. of months in hospital[1]	5.8	(7.3)	4	[1-6]	5.5	(6.1)	4	[1-7]	6.0	(8.4)	4	[1-6]
Patients subject to CTO	70	(61%)	-	-	45	(79%)[2]	-	-	25	(44%)	-	-
No. months on CTO (n=70)[3]	10.5	(13.2)	5	[0-20]	14.8 **	(14.4)	7	[2-27]	6.3 **	(10.4)	0	[0-10]
No. months of involuntary hospitalisation	6.4	(7.1)	4	[2-8]	6.0	(6.2)	4	[2-8]	6.7	(7.9)	4	[2-9]
No. of months of any compulsion	16.9	(14.6)	12	[5-29]	20.8 **	(15.3)	18	[6-36]	13.0 **	(12.7)	9	[3-19]

*[1] Includes index admission; [2] Due to protocol violations in the OCTET Trial, 42 patients randomised to the CTO arm were not placed on a CTO; [3] Multiple periods on CTO included; ** Significant at the < .01 level (Mann-Whitney U test)*

Following randomisation, 113 (99%) of patients had experienced involuntary hospitalisation during the 48-month follow-up (including index admission), spending a mean of 6.4 (SD = 7.1, range = 0 – 39) months under compulsion. During follow-up, 70 (61%) patients had been subjected to a CTO intervention, 45 in the CTO arm and 25 in the Control arm. Only 45 (79%) of patients in the CTO group had been subjected to a CTO – this was due to protocol violations in the OCTET RCT in which 42 patients who were randomised to the CTO arm were never placed on a CTO. The median [IQR] number of months spent on a CTO for the full sample was 5 [0 – 20] months, 7 [2 – 27] for the CTO arm and 0 [0 – 10] for the Control arm. This difference was statistically significant (U = 955, p < .001, *r* = -0.37). There was also a significant between-group difference in the median number of months that patients were subjected to any legal compulsion during follow-up (18 vs. 9) (U = 1109, p < .01, *r* = -0.27).

The mean number of months between baseline and the 48-months follow-up interview was 48.2 (SD = 1.4) for the full sample, 48.3 (SD = 1.5) for the CTO arm and 48.2 (SD = 1.6) for the Control arm.

2.4.4 Characteristics of social networks

The social network characteristics at 48-month follow-up are presented in **Table 3**. Patients had mean of 10.2 (SD = 5.9) contacts in their social network with whom they had been in contact during the past month.

Table 3 Social networks of patients with psychotic illnesses (n = 114) at 48-month follow-up based on encounters in the past month

	Mean	(SD)	Median	[IQR]	(range)
Total					
Total number of contacts in social network	10.2	(5.9)	9	[6-19]	(1 – 29)
Gender of contact					
Male	5.5	(3.9)	5	[3-8]	(0 – 19)
Female	4.7	(3.6)	4	[2-6]	(0 – 23)
Designation of contact					
Relative	4.1	(3.5)	3	[2-9]	(0 – 15)
Health professionals/accommodation staff	1.5	(1.7)	1	[0-2]	(0 – 10)
Hospital and community patients	0.8	(1.4)	0	[0-1]	(0 – 1)
Friend/acquaintance/neighbour/workmate	3.8	(4.3)	2	[1-6]	(0 – 19)
Location of interaction					
Home	4.4	(3.5)	4	[2-6]	(0 – 22)
Healthcare setting	0.5	(1.3)	0	[0-1]	(0 – 9)
Non health setting (anywhere else)	5.2	(5.1)	4	[1-8]	(0 – 25)
Frequency of interaction					
Seen daily (up to 4 times a week)	2.6	(2.8)	2	[1-4]	(0 – 14)
Seen weekly (up to 3 times a week)	3.0	(2.8)	2	[1-4]	(0 – 1)
Seen monthly to fortnightly	2.2	(2.4)	2	[0-3]	(0 – 11)
Less than monthly but seen in the last month	1.3	(1.7)	1	[0-2]	(0 – 7)
Telephone/letter/email/online contact only	1.1	(1.8)	0	[0-2]	(0 – 10)
Intimacy of relationship					
Contacts that would be missed if not seen	7.7	(5.3)	6	[4-10]	(0 – 28)
Confidants	5.0	(3.6)	5	[2-7]	(0 – 15)

Patients had more relatives in their social networks (mean = 4.1, SD = 3.5) than either healthcare professionals/supported accommodation staff (1.5, SD = 1.4) or friends and acquaintances (3.8, SD = 4.3). Overall, relatives made up 40% of patients' social networks. The majority of contacts were seen either at home (4.4, SD = 3.5) or in non-

healthcare settings (5.2, SD = 5.1). Most contacts were seen weekly (3.0, SD = 2.8) followed by daily (2.6, SD = 2.8). Patients reported a mean of 7.7 (SD = 5.3) contacts that would be missed, were they no longer able to have contact with them. Patients had a mean of 5 (SD = 3.6) confidants in their social networks.

2.4.5 Principal findings

Table 4 shows the regression analysis testing the association between the number of months spent on a CTO during follow-up and patients' social network size. No significant association was found for the total number of months (IRR = 0.996) or the number of months calculated as a proportion of months spent in the community (IRR = 0.996). In other words, for each unit increase in the independent variable (i.e. month of compulsion) there was a .04% decrease in patients' social network size, holding all other variables constant.

Table 4 Negative binomial regression testing the association between months of community compulsion and social network size

			95% confidence intervals	
Predictors[1]	**IRR**	**p**	**Lower**	**Upper**
Constant	3.61			
No. of months on CTO treatment	0.996	0.627	0.980	1.012
Constant	3.60			
No. of months on CTO as a proportion of total months in the community	0.996	0.574	0.982	1.010

[1] *Controlling for age, gender, duration of illness, diagnosis, perceived coercion, depression, and days in hospital during follow-up; IRR = Incident Rate Ratio*

2.4.6 Subsidiary findings

There were no significant associations between the number of months of involuntary hospitalisation (IRR = 1.001) or any legal compulsion (IRR = 0.996) and social network size. Results from negative binomial regression analyses are presented in **Table 5**.

Table 5 Negative binomial regression testing the association between (1) months of involuntary hospitalisation and (2) any legal compulsion and social network size

			95% confidence intervals	
Predictors[1]	**IRR**	**p**	**Lower**	**Upper**
Constant	3.66			
No. of months of involuntary hospitalisation	1.001	0.977	0.936	1.071
Constant	3.61			
No. of months of any legal compulsion	0.996	0.629	0.980	1.012

[1] *Controlling for age, gender, duration of illness, diagnosis, perceived coercion, depression, and days in hospital during follow-up; IRR = Incident Rate Ratio*

There were no statistically significant differences in social network characteristics in the CTO and Control groups (**Table 6**). Patients in the CTO arm had a mean of 10.4 (SD = 6.6) vs. 10.0 (SD = 5.3) in the Control group.

Table 6 Social networks by arm of OCTET randomisation for psychosis patients (n = 114) at 48-month follow-up

	Randomisation							
	CTO				Control			
	n = 57				n = 57			
	Mean	SD	Median	[IQR]	Mean	SD	Median	[IQR]
Total								
Total number of contacts in social network	10.4	(6.6)	9	[5-15]	10.0	(5.3)	9	[6-13]
Gender of contact								
Male	5.4	(4.0)	4	[2-8]	5.7	(3.9)	5	[3-7]
Female	5.0	(4.1)	4	[3-7]	4.3	(3.1)	3	[2-6]
Designation of contact								
Relatives	4.0	(3.6)	3	[1-5]	4.2	(3.5)	3	[2-6]
Healthcare professionals / accommodation staff	1.4	(1.3)	1	[0-2]	1.5	(2.0)	1	[0-2]
Hospital and community patients	0.6	(1.2)	0	[0-1]	1.0	(1.5)	0	[0-2]
Friend/acquaintance/neighbour/workmate	4.3	(5.0)	2	[1-8]	3.3	(3.4)	2	[1-5]
Location of interaction								
Home	4.6	(3.7)	4	[2-6]	4.3	(3.4)	4	[2-7]
Healthcare setting	0.4	(0.8)	0	[0-1]	0.7	(1.7)	0	[0-0]
Non health setting	5.4	(5.4)	4	[1-9]	5.0	(4.8)	4	[1-7]

	Randomisation							
	CTO				Control			
	n = 57				n = 57			
	Mean	**SD**	**Median**	**[IQR]**	**Mean**	**SD**	**Median**	**[IQR]**
Frequency of interaction								
Seen daily (up to 4 times a week)	2.6	(2.7)	2	[1-4]	2.6	(3.0)	2	[0-4]
Seen weekly (up to 3 times a week)	3.1	(3.0)	3	[0-5]	2.8	(2.6)	2	[1-4]
Seen monthly to fortnightly	2.4	(2.8)	2	[0-3]	2.1	(2.0)	2	[1-3]
Less than monthly but seen in the last month	1.3	(1.8)	1	[0-2]	1.2	(1.7)	1	[0-2]
Telephone / letter / email / online contact only	1.0	(1.2)	1	[0-2]	1.3	(2.3)	0	[0-2]
Intimacy of relationship								
Contacts that would be missed	7.8	(5.6)	6	[4-11]	7.6	(5.0)	7	[5-10]
Confidants	5.1	(3.6)	5	[3-7]	4.8	(3.7)	4	[2-7]

Table 7 presents patients' social network characteristics stratified by gender, age and ethnicity. Patients aged less than 40 years had significantly more contacts in their social network compared to those aged 40 and older (11.3 vs. 9.0, p <0.05) (t = -2.14, p < .05). There were no statistically significant between-group differences for gender (t = -0.27, p = ns). However, on average, male patients had more male than female contacts in their social networks (mean of 6.1 males vs. 4.0 females), and vice versa for female patients, who had more females than males in their social networks (mean of 6.0 females vs. 4.4. males). There were no statistically significant between-group differences for ethnicity (t = 0.07, p = ns).

Table 7 Social contacts by Gender, Age and Ethnicity for psychosis patients (n = 114)

	Gender				Age				Ethnicity			
	Male		Female		<40 years		≥40 years		White		Other	
	n = 76		n = 38		n = 59		n = 55		n = 56		n = 58	
	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)
Total												
Total number of contacts in social network	10.1	(6.2)	10.4	(5.4)	11.3 *	(6.8)	9.0 *	(4.6)	10.2	(6.3)	10.1	(5.4)
Gender of contact												
Male	6.1	(4.2)	4.4	(3.2)	6.2	(4.6)	4.7	(3.0)	5.2	(3.7)	5.8	(4.2)
Female	4.0	(3.5)	6.0	(3.5)	5.1	(4.1)	4.2	(3.0)	5.0	(4.2)	4.3	(3.0)
Designation of contact												
Relatives	4.0	(3.6)	4.3	(3.4)	5.1	(3.7)	3.0	(3.0)	3.5	(3.2)	4.6	(3.7)
Healthcare professionals	1.4	(1.4)	1.7	(4.3)	1.5	(1.8)	1.4	(1.5)	1.6	(1.5)	1.3	(1.8)
Hospital and community patients	0.8	(1.4)	0.7	(1.3)	0.7	(1.4)	0.9	(1.3)	0.8	(1.3)	0.8	(1.4)
Friend/acquaintance/neighbour/ workmate	6.1	(4.5)	6.1	(4.5)	6.2	(4.9)	6.0	(4.1)	6.7	(4.8)	5.5	(4.1)
Location of interaction												
Home	4.3	(3.8)	4.7	(3.0)	4.8	(3.9)	4.0	(3.0)	4.2	(3.8)	4.6	(3.3)
Healthcare setting	0.6	(1.4)	0.5	(1.1)	0.5	(1.4)	0.6	(1.2)	0.6	(1.2)	0.5	(1.4)
Non health setting	5.2	(4.9)	5.2	(5.5)	6.0	(5.7)	4.4	(4.3)	5.4	(5.2)	5.0	(5.0)

	Gender				Age				Ethnicity			
	Male		Female		<40 years		≥40 years		White		Other	
	n = 76		n = 38		n = 59		n = 55		n = 56		n = 58	
	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)
Frequency of interaction												
Seen daily (up to 4 times a week)	2.5	(2.5)	2.9	(3.4)	2.9	(3.0)	2.3	(2.6)	2.3	(2.6)	3.0	(3.0)
Seen weekly (up to 3 times a week)	3.0	(2.7)	3.0	(2.9)	3.1	(2.7)	2.8	(2.9)	3.2	(2.6)	2.7	(2.9)
Seen monthly to fortnightly	2.2	(2.6)	2.2	(2.1)	2.7	(2.7)	1.7	(2.0)	2.5	(2.7)	2.0	(2.1)
Less than monthly but seen in the last month	1.2	(1.7)	1.3	(1.7)	1.5	(2.0)	1.0	(1.4)	1.2	(1.7)	1.3	(1.7)
Telephone/letter/ email/online contact only	1.2	(2.0)	1.0	(1.6)	1.1	(1.6)	1.2	(2.1)	1.0	(1.5)	1.2	(2.1)
Intimacy of relationship												
Contacts that would be missed	7.5	(5.5)	8.0	(4.8)	8.1	(6.0)	7.7	(4.5)	8.2	(5.3)	7.2	(5.2)
Confidants	5.0	(4.0)	4.9	(2.9)	5.4	(4.0)	4.6	(3.2)	5.0	(3.3)	5.0	(4.0)

*SNS = Social Network Schedule; * Significant at the .05 level (Mann Whitney U test)*

2.4.7 Social network size and clinical functioning

Table 8 presents associations between the total number of contacts and symptom severity and overall functioning. Higher BPRS scores (indicating greater symptom severity) were negatively associated with social network size (Spearman's r = -0.28, p < 0.001). Better overall functioning as measured by the GAF was significantly associated with larger social networks (r = 0.50, p < 0.001). These associations are displayed in **Figures 4** and **5**.

Table 8 Spearman correlations for clinical functioning and number of contacts and confidants

	Total contacts	**Total confidants**	**BPRS**
Total confidants	.594 **	-	-
BPRS	-.281 **	-.203 **	-
GAF	.504 **	.301 **	-.724 **

*BPRS = Brief Psychiatric Rating Scale; GAF = Global Assessment of Functioning. ** Significant at the .001 level*

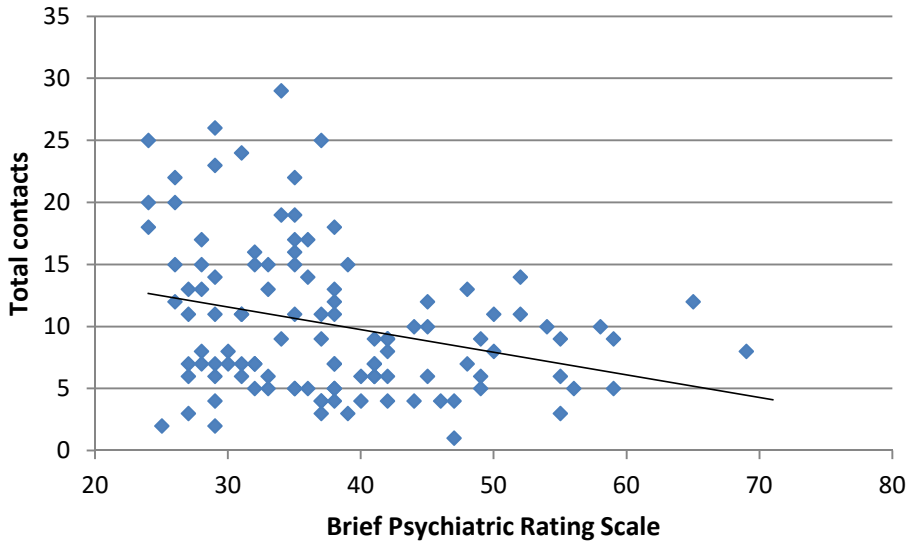
Longitudinal changes in clinical functioning and health-related quality of life are presented in **Table 9**. Patients showed no change in symptom severity or health-related quality of life across the four years of the study, although there was a small (non-significant) improvement in overall functioning between baseline (mean = 38.4) and 48-month follow-up (mean = 44.5). There was a small non-significant improvement in patients' objective social outcomes across the course of the study.

Table 9 Clinical functioning and health-related quality of life during follow-up

	Baseline		12-months		48-months	
	n = 109		n = 86		n = 114	
	Mean	(SD)	Mean	(SD)	Mean	(SD)
Clinical functioning						
BPRS	38.3	(12.1)	34.8	(10.8)	37.8	(9.5)
GAF	38.4	(9.7)	41.3	(13.4)	44.5	(11.1)
Health-related quality of life						
EQ-5D Utilities	0.77	(0.26)	0.75	(0.30)	0.70	(0.30)
Objective social outcomes						
SIX	2.6	(1.1)	2.66	(1.2)	2.78	(1.2)

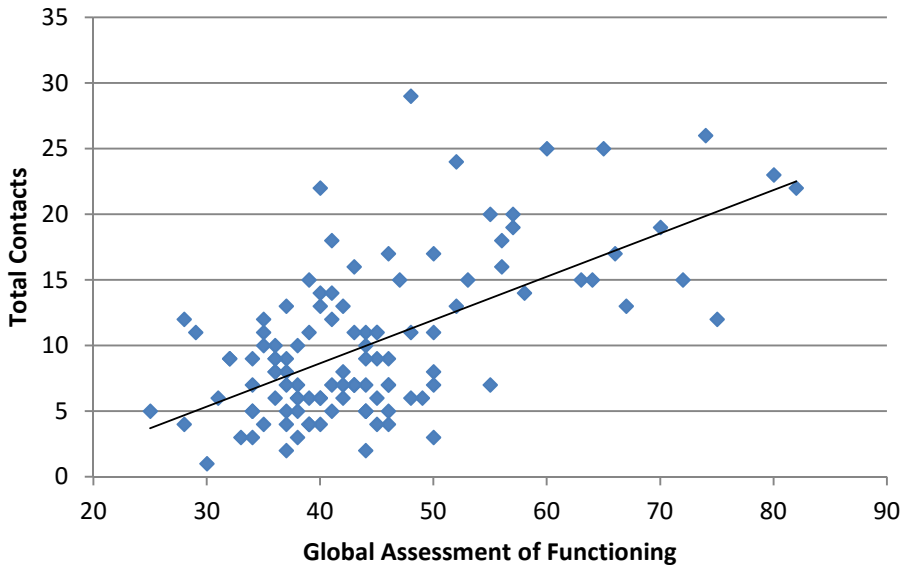
EQ-5D = EuroQol (health-related quality of life); BPRS = Brief Psychiatric Rating Scale; GAF = Global Assessment of Functioning; SIX = Objective Social Outcomes Index

Figure 4 Association between the number of social contacts and symptom severity



r = -.281, p < .001 (Note: higher BPRS score represents greater symptom severity)

Figure 5 Association between the number of social contacts and overall functioning



r = .504, *p* < .001

2.5 Discussion

2.5.1 Main findings

The principal aim of Study 1 was to test whether a longer duration of CTO treatment is associated, positively or negatively, with the number of contacts in patients' social networks. No significant association was found: neither the total duration of CTO treatment nor the duration of CTO treatment calculated as a proportion of months spent in the community were significantly associated with social network size. No statistically significant associations were found for any of the subsidiary outcomes: there was no association between the number of months of involuntary

hospitalisation, or all legal compulsion, and social network size. There were also no significant differences in patients' social network characteristics when stratified by original arm of randomisation (see *Strengths and limitations* in Section 2.5.5 below).

Study 1 failed to find an association between the use of compulsion and the number of contacts in patients' social networks. In all regression analyses, the IRR were very close to 1 and the confidence intervals very small, which suggests that the effect represents a genuine lack of association rather than a result that has arisen due to a lack of statistical power (Field, 2013; Higgins and Green, 2011).

Social network characteristics did not differ by gender or ethnicity (White vs. Other). Patients aged less than 40 years had significantly more contacts in their social networks when compared to patients aged 40 years or older. Symptom severity and overall functioning were significantly associated with patients' social network size: more severe symptoms as measured by the BPRS were significantly negatively associated with larger social networks while better overall functioning measure by the GAF was significantly positively associated with network size.

Compulsory interventions such as CTOs and involuntary hospitalisation can be invasive and socially disruptive for patients (Høyer, 2000; Van Dorn et al., 2006). One might find it surprising, then, that an intervention that forcibly removes an individual from their social context, sometimes for extended periods, or marks them as having a severe mental illness (stigma), is not associated with at least some change in the patient's social network. However, there was no evidence that this was the case. On the other hand, it might be argued that because patients in this study have a history of repeated encounters with compulsory interventions, the effects of these interventions on their lives – whether on their day-to-day social lives or certain

psychological responses to being coerced – may be less dramatic than anticipated by healthcare professionals. The relationship between compulsion – particularly in the community – and social outcomes is explored further in *Chapter 7*.

2.5.2 Social network characteristics

Patients in this study had a mean of 10 contacts in their social networks. This figure is consistent with previous studies of social networks of people with psychotic illnesses but small compared to the general population (Palumbo et al., 2013). In previous studies that used the SNS to assess social networks, there is some variation in the reported mean number of contacts. For example, 16.4 in patients recently discharged from acute psychiatric units, 7.6 (friends and relatives) in Danish sample with first episode psychosis (Thorup et al., 2006), 8.6 for patients attending day hospitals and 24.8 for patients attending day centres (Catty et al., 2005), and 10 (median) (Howard et al., 2000) and 12.8 (Becker et al., 1998) respectively in two epidemiologically representative samples with psychotic illnesses in south London.

In a recent systematic review of the social networks of patients with psychotic illnesses, in which data on social network size was pooled from 20 studies (using a variety of instruments), a mean of 12 social contacts was found (Palumbo et al., 2013). This is very close to the figure of 10 found in Study 1. However, these figures are small compared to the figures of 25 (Pattison et al., 1975) and 40 (Cresswell et al., 1992) reported for the general population. It is worth noting, though, that these latter figures were published before the internet and social media were part of daily interactions, and they may consequently underestimate the size of social networks

among healthy individuals (in Study 1, only five patients used the internet for social networking purposes).

The social networks of patients in this study were made up mostly of family members, with around 40% of contacts being blood relatives or in-laws. This is close to but slightly lower than the 48% reported by in the recent review by Palumbo and colleagues (2013). Contrary to reports in some previous studies of the social networks of people with psychotic illnesses, females in this study did not have larger social network than men (see Palumbo et al., 2013).

An interesting finding in this sample is that there was no difference in composition of the patients' social networks in terms of the number of mental health professionals or family members for patients in the CTO or Control group. This is surprising because patients subjected to longer periods of compulsion might be expected to have a larger proportion of mental health professionals in their social networks due to their frequent contact with mental health services. No evidence of such a relationship was found.

2.5.3 Social network and functioning

Patients' social network size in this study was found to be significantly correlated with symptom severity and even more strongly with overall functioning. Some studies have found a large and significant association between network size and functional outcome (Evert et al., 2003; Howard et al., 2005), and between higher levels of negative symptoms and smaller social networks (Hamilton et al., 1989; Meeks and Hammond, 2001), while others have found no association between network size and psychotic

symptom score (Thorup et al., 2006). Higher levels of depression in schizophrenia have also been linked with smaller social networks (Cohen et al., 1996). Although there is some contradictory evidence, the majority of studies appear to support the findings that a larger social network is associated with fewer symptoms and better overall functioning, as found in the current study.

2.5.4 Compulsion and clinical functioning during follow-up

Data from this study shows that patients were, on average, subjected to protracted periods of compulsion in the long-term. Of patients who were subjected to community compulsion, it amounted to an average of nearly 11 months. Patients also spent, on average, more than six months in hospital involuntarily. When community and hospital compulsion are combined, patients spent nearly one and a half years under compulsion during the four-year follow-up period.

Patients in this study had low levels of functioning at baseline (Burns et al., 2013) and there was little change in functioning over the course of the study, illustrating the chronic nature of illness and high levels of persistent disability in this sample. Whilst the majority of patients (76%) were living independently at 48-month follow-up, nearly half were still living alone and only 6% had part- or full-time work. The mean symptom severity for this sample was essentially unchanged between baseline and 48-months, although there was a small increase in global functioning measured by the GAF (mean GAF scores were still below 50, however, indicating substantial functional impairment). There was, however, a small but non-statistically significant improvement in patients' objective social outcomes across the four years of the study,

although this may reflect selection bias because only patients who were mentally stable and living in the community – i.e. those who were doing better – were included in the analysis.

2.5.5 Strengths and limitations

Baseline social network data

Due to missing data the size of patients' baseline social networks could not be controlled for in the regression analyses. This is a limitation of the study. An attempt was made to compensate for the missing data by selecting proxy indicators of patients' baseline social networks – the following variables were added to the regression model as covariates in the principal analyses only: living alone vs. living with friends/family, being able to meet socially with friends/relatives (yes vs. no) ('Are you able to meet socially with friends and relatives?') (Simon et al., 2013), having met socially with friends within the last week (yes vs. no) ('Have you met socially with a friend within the last week?') (Priebe et al., 2008). No significant association was found between the baseline proxy indicators and patients' social network size at 48-months. When entered into the regression analysis as covariates, the baseline proxy indicators did not alter the statistical significance of the model and the IRR and confidence intervals remained remarkably small.

The fact that baseline social network size could not be controlled for may have introduced certain biases into the analysis. For example, one might question whether patients with smaller baseline social networks (and therefore less social support) were

more likely to have been placed on a CTO. This is a possibility although it is unlikely to have occurred in the first year of the study because of the largely successful randomisation process at baseline which determined whether or not a patient was placed on a CTO. Nevertheless, a bias may have been introduced after the first year of the study when patients who were not randomised to the CTO arm were subsequently placed on CTOs based on a clinician's judgement that they might benefit from such an intervention.

Conceptual and measurement issues

Some of the more general challenges faced by researchers using social network measures were discussed in the Introduction but there are several limitations relating to the use of the SNS specifically. The SNS is a relatively blunt instrument: it does not distinguish between different kinds of support (emotional, practical, etc.) or the directionality of the relationship – for example, some relationships such as those in which the patient is a significant care-giver might provide little support to the patient and in fact take considerable resources away from them. The time frame of one-month has no theoretical basis and might be considered relatively long making it susceptible to recall bias.

A further concern that might be raised about the reliability of the SNS – and indeed all existing social network measures – is the reliance on self-reported social networks. Self-report data can threaten validity in a number of ways, including through lapses in memory, recall bias and deliberate falsification. In this study, some verification of patients' social networks was possible through cross checks with medical records and healthcare professionals, but this cannot be completely reliable or objective. In the

future, studies might devise more sophisticated methods such as the use of text messaging or day-by-day diaries used to record interactions with contacts in real time. While self-report data are always susceptible to bias, this limitation is not unique to the SNS and affects a vast number of instruments reported in the psychiatric literature.

A further more general challenge relating to the measurement of social networks is the heterogeneity of the concepts used and how they are assessed across studies (Palumbo et al., 2013). There is still no consensus about which types of contacts – relatives, friends, acquaintances, etc. – are most relevant and ought to be included or even how to define the term 'friendship'. An important objective for future studies is to develop and apply comprehensive and standardised instruments that assess both objective (quantitative) and subjective (qualitative) social network characteristics (Palumbo et al., 2013).

2.5.6 Limitations of the OCTET Social Outcomes Studies (Studies 1 to 3)

This was an association study and no causation can be implied. The effects of randomisation were highly diluted at 48-months follow-up and this limits the conclusions that can be drawn from the between-group comparisons (CTO treatment vs. Control). Patients with psychotic illnesses are frequently non-adherent with medication and difficult to engage with mental health services and while the challenges of conducting a follow-up study of this kind should be acknowledged, the sample is nevertheless relatively modest in size. In some cases, this may have limited power to detect significant differences, particularly in the smaller between-group comparisons.

Patients in this follow-up study were selected on the basis that they were resident in geographically accessible locations and due to reach their 48-month follow-up date between January 2013 and December 2014 (and consequently could be seen within the timeframe of my DPhil). This may have introduced a selection bias. However, comparison of patient characteristics with the overall OCTET Trial sample did not provide evidence for such a bias, with the exception the ethnic composition. The larger number of ethnic minority patients in the follow-up sample is probably due to the fact that more patients were followed up in cities where the majority of ethnic minorities are known to live. Follow-up of a random selection of participants in the OCTET Trial would have helped to reduce this bias, although would have required considerably more resources to implement.

Potentially more concerning is the bias that only community patients who were willing to participate were included in the analysis. Patients who were too unwell or in hospital at the point of follow-up were not included in the analysis so it could be argued, at least in theory, that these patients had the greatest potential to benefit from the CTO intervention. This is a possibility that cannot be completely ruled out. Nevertheless, it seems unlikely that inclusion of these particularly unwell or unwilling patients would have affected the overall results given the almost complete absence of an effect in the regression analyses including the extremely small confidence intervals (Field, 2013; Higgins and Green, 2011).

The fact that 44 patients (39%) were never subjected to CTO treatment during the four year follow-up means that the main predictor (number of months on compulsion) in the regression analysis had a large number of zeros, which may have

reduced statistical power. Removal of these cases from the analyses did not alter the results however.

The protocol violations that occurred during the OCTET Trial limit the conclusions that can be drawn from analyses based on the arm of randomisation. In this study, only 45 (79%) of the 57 patients in the CTO arm were actually subjected to a CTO during follow-up; conversely, 25 (44%) of patients in the Control arm were put on a CTO during follow-up. During the RCT, there were 42 protocol violations in the CTO group and 46 in the Control group and, during the subsequent 36-months of follow-up, many more patients who were in the Control group were placed on a CTO. Problems of this kind remain a significant challenge in CTO research, particularly in follow-up studies, and results should be interpreted with caution.

A further more general limitation relates to the study design and the reliance on cross-sectional data at 48-months. A potentially stronger design would involve the inclusion of a suite of social outcome measures in a well-controlled RCT (baseline and 12-months at the least), including 48-months follow-up with the same measures, with particular attention given to potential crossovers between the randomised groups during the follow-up period. An alternative design, arguably more feasible to implement, would involve a prospective observational study in which social outcome data are assessed at baseline, 12-months, 36-months, and 48-months, to allow longitudinal changes in social outcomes to be observed.

2.5.7 Conclusions

This study found that neither the duration of CTO treatment nor the duration of involuntary hospitalisation were associated with significant differences in the size of patients' social networks. The social network characteristics of patients in this study were comparable to previous studies of the social networks of patients with psychotic illnesses: patients had relatively small social networks containing a large number of relatives when compared with the general population. There were no significant between group differences in social network size when analysed by gender or ethnicity although patients aged less than 40 years of age had significantly larger networks compared to patients aged 40 or older. The results showed that there was little improvement in clinical functioning, health-related quality of life or objective social outcomes during the course of the study, indicating the generally chronic course of illness with high levels of persistent disability.

Chapter 3: Social inclusion and psychiatric compulsion

Isolation is the sum total of wretchedness to a man

– Thomas Carlyle

3.1 Introduction

3.1.1 Background: from exclusion to inclusion

Social inclusion and exclusion may be as old as humanity itself. Nearly every known society has customs or taboos about the social rejection and acceptance of certain individuals or groups (Allman, 2013). One of the earliest recorded accounts of social exclusion is attributed to the ancient Greeks who described the use of 'ostracism' as means of excluding political rivals from society (Kagan, 1961). Nearly 2500 years later the French sociologist, Emil Durkheim, began to systematically examine 'social cohesion' as a social phenomenon in the late 19th century (Berkman et al., 2000). Durkheim observed that suicide rates were higher in certain groups or social classes, particularly those that were socially isolated, which he attributed to a breakdown in social cohesion. Durkheim's ideas were influential in shaping early sociological explorations of stigma, later developed in the seminal work of Erving Goffman.

Writing in 1950s America, Goffman developed his theory of stigma as a recognisable form of social exclusion in which an individual becomes discredited and is consequently denied full participation in civil society (Kurzban and Leary, 2001), an idea which continues to shape conceptions of social exclusion today (Allman, 2013).

The modern concept of social exclusion arguably has its origins in France in René Lenoir's political tome *Les exclus*. Lenoir (1973), whose work initially focused on disabled and socially and economically destitute groups, described the socially excluded as those individuals who fell through the state's social security net, such as unemployed single parents, the uninsured unemployed, or those without recourse to public funds. The concept gradually came to include any individual or group on the margin of society and led to a strong national rhetoric about the threat of social exclusion to the ideal of equality enshrined in the French constitution (Silver, 1995). It has been suggested that the introduction of the term 'social exclusion' into social policy reflects the view that 'poverty was no longer the right word to use to describe the plight of those marginalised from mainstream society' (Williams and White, 2003, p.91). Lenoir's work was influential in shaping French social policy of the 1980s, leading to one of first attempts by a national government to reduce social exclusion, and subsequently incorporated into European Community social policies in the early 1990s (Wilson, 2006).

In the United Kingdom, the concept of social exclusion is thought to have its origins in the critical social policy of the 1980s (Levitas, 2006), gaining particular prominence following the introduction of the Social Exclusion Unit in 1997. The Social Exclusion Unit was set up by the British government to generate advice and policy analysis as part of its drive to understand and combat the problem of social exclusion (Social

Exclusion Unit, 2004). One of the Unit's early findings, which helped shape mental health policy and research agendas in the late 1990s, was that people with severe mental illness were one of the most socially excluded groups in society (Huxley and Thornicroft, 2003; Social Exclusion Unit, 2004).

Social exclusion and mental health in the UK

Dozens of published studies since have echoed the findings of the Social Exclusion Unit that a large number of people living with mental illness are excluded and marginalised from society (Huxley and Thornicroft, 2003; Huxley et al., 2012, Schneider and Bramley, 2008). For example, less than 10% of people with severe mental illness in the United Kingdom are employed, lower than any other disabled group in society (Labour Force Survey, 2002). Those who are employed work fewer hours for less pay (Evans and Huxley, 2000; Labour Force Survey, 2002; Meltzer et al., 1995) they are more likely to be homeless (Rees, 2009) and to live in areas of high social deprivation (Murali and Oyebode, 2004). Many lack social capital (Kawachi et al., 2008) and suffer high levels of stigma and discrimination (McDaid, 2008; Sayce, 2001) which further sustains lack of engagement in the workforce and other social institutions. These aspects of 'exclusion' both individually and cumulatively increase disability and impede recovery (Huxley et al., 2012; Perkins and Repper, 1996; Sayce, 2001; Slade, 2009).

The majority of relevant studies in the mental health literature have focused on the understanding and measurement of social exclusion and inclusion among the common mental disorders (such as anxiety and depression), but much less attention has been paid to the more severe and chronic psychotic illnesses (Boardman et al.,

2010; Killaspy et al., 2013). This is perhaps surprising since there is evidence that compared to people with common mental disorders, patients with psychotic illnesses are more likely to be unemployed, to lack adequate housing, to drop out of education, to live in poverty and to be socially isolated (Killaspy et al., 2013; Marwaha et al., 2007; Meltzer et al., 1995; Mind, 2008). This suggests that further work on social inclusion among patients with psychotic illnesses is important and needed.

Making social inclusion a policy priority

The need to improve social inclusion for people living with mental illness is increasingly recognised by researchers and policy makers worldwide (Baumgartner and Burns, 2014). The Global Mental Health Initiative has identified the top 40 challenges for the next decade that will improve the lives of people living with mental and neurological disorders. The second most highly ranked of these challenges is to 'develop culturally informed methods to eliminate the stigma, discrimination and social exclusion of patients and families across cultural settings' (Collins et al., 2011, p.29). The World Health Organisation (WHO) has also developed broad pragmatic guidance for countries to promote the social inclusion of individuals living with mental illness. The stated purpose of this legislation is to 'assist the reintegration of people with mental disorders into all aspects of community life, thus improving their overall quality of life' (WHO, 2007, p.9). In general, the contemporary global policy guidance on social inclusion of individuals with mental disorders is sweeping and does not focus on the definitions or the details of measurement (Baumgartner and Burns, 2014). Efforts to develop viable measures to assess interventions that reduce social exclusion and improve social inclusion are hampered by conceptual and

methodological uncertainties and by vague and contested definitions (Morgan et al., 2007).

3.1.2 A conceptual history: exclusion or inclusion?

Applied and theoretical interest from the fields of sociology, anthropology, occupational therapy, psychology, psychiatry and nursing have contributed to the conceptual development of social exclusion and inclusion (e.g. Allman, 2013; Huxley et al., 2012; Le Boutillier and Croucher, 2010; Morgan et al., 2007; Repper and Perkins, 2003). There is wide consensus that social exclusion and inclusion are complex, multi-dimensional constructs that elude easy definition and the vast majority of studies in the mental health literature provide no definition of either concept (Baumgartner and Burns, 2014; Morgan et al., 2007).

Social exclusion

The terms *social exclusion* and *social inclusion* are both widely used within the mental health and social policy literature. The terms are closely linked although the choice of terminology appears to depend to some degree on authors' theoretical backgrounds, intellectual sympathies and idiosyncratic aims (Wright and Stickley, 2012). Early research and policy discourse focused on the concept of social exclusion, of which there are dozens of definitions in the literature, each emphasising a slightly different aspect of the concept (Huxley et al., 2012; Morgan et al., 2007).

The following working definition of social exclusion, proposed by Levitas and colleagues (2007, p.9), captures many of the dimensions of exclusion reflected in the literature:

> *Social exclusion is a complex and multi-dimensional process. It involves the lack or denial of resources, rights, goods and services, and the inability to participate in the normal relationships and activities, available to the majority of people in a society, whether in economic, social, cultural or political arenas. It affects both the quality of life of individuals and the equity and cohesion of society as a whole.*

Many of the difficulties in defining social exclusion arise, at least in part, because the term shares considerable overlap with other social concepts (Allman, 2013; Morgan et al., 2007). Social exclusion has much in common with certain definitions of poverty, for example, and the concepts have even been treated as synonymous (e.g. Howarth et al., 1998). However, while poverty usually refers to 'economic, material, or resource-based' deprivation, social exclusion is understood to be a broader concept that offers a more holistic understanding of deprivation and disadvantage (Silver and Miller, 2003). Within the literature, concepts associated with social exclusion and inclusion include, but are not limited to, socio-economic status, citizenship, education, social cohesion, social capital, social support, and social participation and poverty (Huxley et al., 2012). Most definitions recognise the multi-dimensionality of social exclusion, its dynamic nature (i.e. participation will vary over time), and that it can occur at multiple levels (e.g., individual, household, community, society) (Morgan et al., 2007). Although no widely accepted definitions of social exclusion exist, lack of participation in mainstream economic, political, social and cultural activities is a core feature of most definitions (Morgan et al., 2007).

Social inclusion

Over the past decade and a half, mental health research and policy discourse has shifted from the previously dominant concept of social exclusion towards the concept of social inclusion (Secker, 2009). Although the concept of social inclusion shares many of the same conceptual hurdles as social exclusion, the choice of terminology reflects a certain progression in terms of what is being measured or rather should be measured. According to several selected definitions, social inclusion is:

> *… about each person taking part in society and having control over his or her own resources. It is also about a community that cares for its members, makes them feel welcome and is willing to adjust to fit their various needs* (Marino-Francis and Worrall-Davies, 2010, p.38)

> *… a person's right to participate as an equal citizen in all the opportunities available, employment, education and other social and recreational activities* (Slade, 2009, p.11)

> *… full access to mainstream statutory and post-16 education, open employment and leisure opportunities alongside citizens who do not bear these (mental illness) labels* (Bates and Repper, 2001, p.19)

> *… a virtuous circle of improved rights of access to the social and economic world, new opportunities, recovery of status and meaning and reduced impact of disability* (Sayce, 2001, p.122)

> *… A process which ensures that those at risk of poverty and social exclusion gain the opportunities and resources necessary to participate fully in economic, social*

> *and cultural life and to enjoy a standard of living and wellbeing that is considered normal in the society in which they live. It ensures that they have greater participation in decision-making which affects their lives and access to their fundamental rights (as defined in the Charter of Fundamental Rights of the European Union)* (Council for the European Union, 2003, p.9)

While these definitions have much in common, there is no single accepted definition or even agreement about what social inclusion is (Huxley et al., 2012; Morgan et al., 2007; Repper and Perkins 2003). In what is one of the most extensive recent reviews of the social inclusion literature, Huxley and colleagues (2012) do not provide an authoritative definition of the concept. As with social exclusion, social inclusion is complex and multifaceted and overlaps with concepts such as citizenship, social cohesion, social capital, social support, social participation, social networks, quality of life and well-being (Huxley et al., 2012). A review of the social inclusion literature to develop a framework to guide the selection of items and measures for use in a social inclusion measure in Australia concluded that 'a broad suite of indices would be required to capture all of the relevant aspects of inclusion' (Wilson, 2007).

The recent emphasis on social inclusion rather than exclusion is evidenced by its growing prominence in a number of recent literature reviews (Baumgartner and Burns 2014; Coombes et al., 2013; Huxley et al., 2012) and may reflect an increasing emphasis on measuring and improving social participation and recovery (Secker, 2009; Slade, 2009). In light of this emerging conceptual consensus, which is an important methodological step towards operationalization and measurement, I chose to emphasise the concept of social inclusion rather than exclusion in this study.

This brief review of the literature shows that the concepts of social exclusion and inclusion require further conceptual development if they are to be useful for measurement purposes. Several commentators have noted that this work is not merely an academic matter and that it has significant potential value for improving our understanding of the lived experience of people with mental illness (Morgan et al., 2007; Repper and Perkins, 2003; Sayce, 2001). Full examination of this subject, including a critique of the concept of social inclusion, is beyond the scope of this DPhil and reviews of this literature can be found elsewhere (e.g. Huxley et al., 2012; Sayce, 2001; Secker, 2009; Schneider and Bromley, 2008).

3.1.3 Measuring social inclusion in mental health research

The need to improve social inclusion among people with mental illness is increasingly recognised in mental health research and policy circles and there has been a recent surge in the development of social inclusion measures (Coombes et al., 2013; Baumgartner and Burns, 2014; Huxley et al., 2012; Mezey et al., 2012). The majority of these instruments are concerned with measuring social inclusion rather than social exclusion. The ongoing conceptual uncertainties remain a major impediment to the development of social inclusion instruments, particularly with respect to the problem of deciding which dimensions of social inclusion are most relevant to the concept (Cobigo and Stuart, 2010; Huxley et al., 2012; Morgan et al., 2007; Wilson, 2006).

It is generally accepted that both objective indicators and subjective experience are relevant in the measurement of social inclusion (Baumgartner and Burns, 20134; Priebe, 2007). *Objective* indicators include measureable events relating to social

participation, such as having a job, voting in local or national elections, meeting socially with friends, and participating in community activities. Participation can usually be quantified by counting the frequency, duration and range of participation in relevant social domains (e.g., 'Did you vote in the last general election?', 'How many hours did you work in the last week starting on Monday', 'How often do you have friends or neighbours around to your house?'). *Subjective* indicators represent an individual's subjective appraisal of their own participation in relevant social domains. Subjective indicators are usually obtained by asking patients how they feel about opportunities to participate (e.g., 'How do you feel about your opportunities to find suitable work?', 'How do you feel about the extent to which you are included in society?') (Huxley et al., 2012).

It is generally accepted that a viable measure of social inclusion will include both subjective and objective indicators of inclusion (Huxley et al., 2012; Priebe, 2007). Additionally, a measure designed for use in research or routine clinical assessments should be brief, have good psychometric properties – particularly reliability and validity and sensitivity to change – and be straightforward to administer, score and interpret (Coombs et al., 2013; Guyatt et al., 1992; Streiner and Norman, 2008). There are no widely used measures of social inclusion and although the majority of existing measures meet some of these criteria, none meet them all (Baumgartner and Burns, 2014; Coombs et al., 2013).

The most recent reviews of English language social inclusion measures designed for use in a mental health context identified five and ten viable instruments respectively (Baumgartner and Burns, 2014; Coombs et al., 2013). Both studies note the small number of available instruments and the absence of any obvious front-runner.

Moreover, most of the available instruments have undergone quite limited psychometric testing and require further validation and testing. Coombs et al. (2013) conclude that the Activity and Participation Questionnaire (APQ-6) and the Social and Community Opportunities Profile (SCOPE) are the most robust and show the best potential for further testing. Baumgartner and Burns (2014) drew similar conclusions, noting that the SCOPE was one the more promising social inclusion measures, although further testing of the instrument was advised.

Given its apparent robustness, and the limited availability of other relevant measures at the time, I selected the SCOPE as a measure of social inclusion for Study 2. A further aim of this DPhil was to evaluate the feasibility and psychometric properties of the SCOPE in a clinical research setting and this is the subject of *Chapter 5*.

The SCOPE was developed in the UK as part of a Health Technology Assessment programme of the National Institute for Health Research to produce a reliable and valid social inclusion measure for use with people with mental illness both in research and in routine clinical settings (Huxley et al., 2012). The instrument was initially developed in a longer form containing 121 items and subsequently reduced to a 48-item 'short version' using factor analysis. Unless otherwise specified, reference to the SCOPE in this DPhil thesis is to the short version throughout. The instrument is comprised of two sub-scales: (1) *Satisfaction with Opportunities* and (2) *Perceived Opportunities*, as well as a question asking about the patient's subjective perception of their overall inclusion ('Overall, how do you feel about the extent to which you are included in society?'). The instrument contains 34 further questions that ask about 'objective' participations/inclusion, such as whether or not the patient has employment, housing or a partner (see *Instruments used in the study* in the Methods

section). Full description of the instrument including development and initial testing is described elsewhere (Huxley et al., 2012).

3.1.4 Psychiatric compulsion and social inclusion (Study 2)

It was discussed in *Chapter 1* that the use of compulsion in psychiatry has been the subject of considerable past and ongoing controversy (Høyer, 2000; Szasz, 1998; Wynn, 2006). Much of this debate has centred on the use of legal coercion in the community, or community treatment orders (CTO). The controversy surrounding the use of CTOs has been sustained by the lack of convincing evidence for their effectiveness, but recent systematic reviews indicate no benefit in terms of reduced relapse and readmission to hospital (Kisely et al., 2014; Kisely and Hall, 2014; Maughan et al., 2014; Rugkåsa et al., 2014a).

The three RCTs of CTOs conducted to date have two important limitations however. First, none have been longer than 12-months (Burns et al., 2013; Steadman et al., 2001; Swartz et al., 1999) so the long-term effects of CTOs remain uncertain (Rugkåsa et al., 2014a). Second, these trials have focused almost exclusively on clinical outcomes (readmission to hospital) and there has been only limited critical discussion and empirical evaluation of CTO effects on patients' social outcomes and broader welfare (Kisely et al., 2014). There has been no test of the relationship between CTOs and any specifically designed social inclusion measure.

We designed a follow-up study to test whether the total duration of CTO treatment was associated with more or less favourable social inclusion at 48-months follow-up (Study 2). A sub-sample from the OCTET Trial was followed up four years after

randomisation and assessed by research interview on a battery of social and clinical functioning measures.

A detailed description of the rationale for testing the association between compulsion and social outcomes can be found in *Chapter 1* under the sub-heading 1.5.4 *Study rationale and hypotheses*.

3.2 Research questions

Principal questions

1. Is a longer duration of CTO treatment over 48-months associated with higher or lower levels of social inclusion in terms of (1) Perceived opportunities, (2) Satisfaction with opportunities, and (3) objective indicators of social inclusion at follow-up?
2. Is a longer duration of CTO treatment over 48-months, calculated as a *proportion* of time spent in the community, associated with higher or lower levels of social inclusion in terms of (1) Perceived opportunities, (2) Satisfaction with opportunities, and (3) objective indicators of social inclusion at follow-up?

Subsidiary questions

1. Is a longer duration of involuntary hospitalisation over 48-month follow-up associated with higher or lower levels of social inclusion in terms of (1) Perceived opportunities and (2) Satisfaction with opportunities at follow-up?
2. Is a longer duration of *any* legal compulsion (hospital and community) over 48-month follow-up associated with higher or lower levels of social inclusion in terms of (1) Perceived opportunities and (2) Satisfaction with opportunities at follow-up?
3. Do patients who were randomised to the CTO arm have higher or lower levels of social inclusion than patients in the voluntary arm in terms of Satisfaction with opportunities, Perceived opportunities, and perceived social inclusion at follow-up?
4. Is gender (Male vs. Female), age (<40 years vs. ≥40 years) or ethnicity (White vs. Other) associated with higher or lower levels of Satisfaction with Opportunities, Perceived opportunities, or perceived social inclusion?
5. What are the objective indicators of social inclusion for patients with psychotic illnesses and how do they compare with clinical and non-clinical samples reported by Huxley et al. (2012)?

3.3 Methods

Unless indicated otherwise, the sample, design, data collection procedure, and data management used in Study 2 are the same as those used in Study 1, *Chapter 2*. As for study 1, I carried out all patient interviews, data cleaning, entry, and analysis.

3.3.1 Instruments used in the study

Social inclusion: *The Social and Community Opportunities Profile (SCOPE – short version)* (Huxley et al., 2012) is a 48-item self-complete or clinician/researcher assisted questionnaire developed to assess social inclusion in mentally ill populations. The instrument contains two sub-scales, *Satisfaction with Opportunities* and *Perceived Opportunities*; the Satisfaction with Opportunities contains 8 items scored on a 1-7 Likert scale (terrible, displeased, mostly dissatisfied, mixed, mostly satisfied, pleased, delighted), while the Perceived Opportunities contains 5 items scored on a 1-5 Likert scale (opportunities are extremely restricted, opportunities are quite limited, mixed, some good opportunities, plenty of opportunities). Scores for both sub-scales are summed and then divided by the number of items. The instrument asks about patients' subjective perception of their own social inclusion and also has a range of objective indicators of participation and inclusion (e.g. employment, accommodation, social contact). Objective indicators of social inclusion can be compared with general population data from UK national surveys (e.g. Crime Survey for England and Wales).

Objective social outcomes: *The Objective Social Outcomes Index (SIX)* (Priebe et al., 2008). See Methods section of the Social network study, *Chapter 2* (p.54).

Perceived coercion: *Admission Experience Survey (AES)* (Gardner et al., 1993). See Methods section of the Social network study, *Chapter* (p.54).

Instruments used in this study are reproduced in full in *Appendix I*.

3.3.2 Statistical analyses

Principal analyses

After testing for violation of model assumptions, multiple linear regression analyses were used to test for an association between the duration of CTO treatment and (1) Satisfaction with Opportunities and (2) Perceived Opportunities and (3) objective indicators of social inclusion. Analysis (1) and (2) were based on the sub-scales of the SCOPE; since objective indicators captured by the SCOPE cannot be summed into a single index (Huxley et al., 2012), the Objective Social Outcomes Index (SIX) was used to test the association between the duration of CTO treatment and objective indicators of social inclusion.

For question 1, the total days of CTO treatment during follow-up (which includes multiple periods of CTO treatment) was used as the main predictor. All analyses controlled for the following factors: age, gender, duration of illness, diagnosis (schizophrenia vs. other), illness severity (total days in hospital during follow-up) and perceived coercion at 48-month follow-up. These analyses were repeated for all three outcomes using the total duration of CTO treatment calculated as proportion of time (days) in the community as the main predictor. To facilitate interpretation of the regression analyses, the number of days of CTO treatment and number of days of

involuntary hospitalisation were converted into months by dividing the total number of days by 30.43 prior to analysis. This reduced the number of decimal places in the beta coefficients making the ratio between the predictor and outcome larger and therefore easier to interpret.

Subsidiary analyses

The linear regression model described above was used for the two subsidiary questions by replacing the main predictor with the *total number of months of involuntary hospitalisation* and the *total number of months of any compulsion* in the respective analyses. A between-groups analysis using randomisation as the grouping variable was conducted for the SCOPE's two sub-scales (Perceived Opportunities and Satisfaction with Opportunities) and the perceived social inclusion question.

Mean scores for Satisfaction with Opportunities, Perceived Opportunities, and perceived social inclusion were analysis by gender (Male vs. Female), age (<40 years vs. ≥40 years) and ethnicity (White vs. Other).

Objective indicators of social inclusion obtained from the SCOPE were compared with data from UK national surveys reported by Huxley et al. (2012) and with two patient groups and a group of healthy controls. These groups are described as: Common Mental Disorders such as anxiety and depression (CMD) (n = 40, age = 51 (SD = 21), range = 16 – 92); Mental Health Service Users (MHSU) (n = 43, age = 49 (SD = 12), range = 21 – 67) ('people with severe and chronic mental health problems' such as schizophrenia and bipolar disorder, but in remission i.e. 'discharged and surviving in the community'); and a group of Mental Health Control (healthy controls) (MHC)(n

= 212, 55 (SD = 21), range = 16 – 92) (Huxley et al., 2012). There is little further information about the socio-demographic and clinical characteristics of these patients groups (Huxley et al., 2012); this is discussed as a limitation of the instrument in *Chapter 5*.

3.4 Results

Participant flow and follow-up is described in the Results of Study 1, *Chapter 2* (p.60). Complete social inclusion data were available for 114 patients and all analyses were carried out on this sample. The socio-demographic and clinical characteristics of the sample are presented in **Table 1**, *Chapter 2* (p.62). Interventions and changes in legal status during 48-month follow-up are presented in **Table 2**, *Chapter 2* (p.65).

As in Study 1, cases that did not have complete data for the outcome and all predictors were dropped from the regression analyses. Thus, of the 114 eligible patients, nine were removed because of missing data for the AES-PC (the AES-PC was used to control for perceived coercion at follow-up but could not be completed by patients who had been discharged from mental health services since the instrument asks about experiences of pressure/coercion in relation to the patient's care coordinator and CMHT in the last six months). One further patient was dropped because their duration of illness was unknown. All regression analyses were consequently conducted on a sample of 104 patients.

3.4.1 Principal findings

Results of the linear regression analyses testing the association between duration of CTO treatment and the social inclusion sub-scales are presented in **Table 10**. There was no significant association between the number of months of CTO treatment during follow-up and Satisfaction with Opportunities (B = -0.005, p = ns) (95% CI = -0.02 – 0.01) including when the number of months of CTO treatment was calculated as a proportion of total months spent in the community (B = 0.003, p = ns) (95% CI = -0.01 – 0.01). Similarly, there was no significant association between the number of months of CTO treatment and Perceived Opportunities (-0.003, p = ns) (95% CI = -0.1 – 0.01), including when the number of months of CTO treatment was calculated as a proportion of total months spent in the community (-0.001, p = ns) (95% CI = -0.01 – 0.01).

Table 10 Multiple linear regression testing the association between the number of months of CTO treatment over 48-months and social inclusion at follow-up

				95% confidence interval for B	
Predictors [1]	**B**	**SEB**	**p**	**Lower**	**Upper**
1. Satisfaction with Opportunities					
Constant	6.323				
No. of months of CTO treatment	-0.005	0.007	0.445	-0.018	0.008
R^2 = 0.19					
Constant	6.347				
No. of months on CTO as a proportion of total months in the community	-0.003	0.005	0.580	-0.013	0.008
R^2 = 0.19					
2. Perceived Opportunities					
Constant	4.189				
No. of months on CTO treatment	-0.003	0.006	0.631	-0.014	0.008
R^2 = 0.08					
Constant	4.285				
No. of months on CTO as a proportion of total months in the community	-0.001	0.005	0.748	-0.010	0.008
R^2 = 0.09					

[1] *Controlling for age, gender, duration of illness, diagnosis, perceived coercion and days in hospital during follow-up*

Regression analyses testing the association between the duration of CTO treatment and objective indicators of social inclusion as measured by the SIX are presented in **Table 11**. There was no significant association between the number of months of CTO treatment during follow-up and Satisfaction with Opportunities (B = -0.003, p = ns)

(95% CI = -0.01 – 0.01) including when the number of months of CTO treatment was calculated as a proportion of total months spent in the community (B = 0.001, p = ns) (95% CI = -0.01 – 0.01).

Table 11 Multiple linear regression testing the association between CTO treatment over 48-month follow-up and objective social inclusion indicators

				95% confidence interval for B	
Objective Social Outcomes Index (SIX) [1]	**B**	**SEB**	**p**	**Lower**	**Upper**
Constant	3.211				
No. of months of CTO treatment	-0.003	0.009	0.771	-0.020	0.015
R^2 = 0.36					
Constant	3.145				
No. of months on CTO as a *proportion* of total months in the community	-0.005	0.007	0.453	-0.020	0.009
R^2 = 0.42					

[1] *Controlling for age, gender, duration of illness, diagnosis, perceived coercion and days in hospital during follow-up*

Small confidence intervals were observed in all regression analyses. Likewise, R^2 values were all modest, indicating that the regression models explained only a small amount of the variance between the duration of compulsion and social inclusion.

3.4.2 Subsidiary findings

Table 12 shows that there was no significant association between the number of months of any legal compulsion (hospital and community) and either the Satisfaction with Opportunities (B = -0.005, p = ns) (95% CI = -0.02 – 0.01) or Perceived Opportunities (B = -0.002, p = ns) (95% CI = -0.01 – 0.01) sub-scales of the SCOPE.

Table 12 Multiple linear regression testing the association between months of any legal compulsion during 48-month follow-up and SCOPE social inclusion sub-scales

				95% confidence interval for B	
Predictors[1]	**B**	**SEB**	**p**	**Lower**	**Upper**
1. Satisfaction with Opportunities					
Constant	6.394				
Months on any legal compulsion	-0.005	0.007	0.441	-0.018	0.008
R^2 = 0.19					
2. Perceived Opportunities					
Constant	4.190				
Months on any legal compulsion	-0.002	0.006	0.752	-0.013	0.009
R^2 =0 .09					

[1] *Controlling for age, gender, duration of illness, diagnosis, perceived coercion and days in hospital during follow-up*

Likewise, there was no significant association between the number of months of involuntary hospitalisation and either the Satisfaction with Opportunities (B = 0.001, p = ns) (95% CI = -0.56 – 0.056) or Perceived Opportunities (B = 0.017, p = ns) (95% CI = -0.030 – 0.065) sub-scales of the SCOPE (**Table 13**).

Table 13 Multiple linear regression testing the association between the number of months of involuntary hospitalisation and SCOPE social inclusion sub-scales at follow-up

				95% confidence interval for B	
Predictors[1]	**B**	**SEB**	**p**	**Lower**	**Upper**
1. Satisfaction with Opportunities					
Constant	6.255				
Months of involuntary hospitalisation	0.000	0.028	.994	-0.056	0.056
R^2 = 0.18					
2. Perceived Opportunities					
Constant	4.193				
Months of involuntary hospitalisation	0.017	0.024	.731	-0.030	0.065
R^2 =0.09					

[1] *Controlling for age, gender, duration of illness, diagnosis, perceived coercion and days in hospital during follow-up*

Despite the longer duration of CTO treatment during follow-up, there were no statistically significant differences in scores on the SCOPE sub-scales when grouped by arm of randomisation (**Table 14**).

Table 14 Duration of compulsion and social inclusion at 48-months by OCTET arm of randomisation

	CTO		Control	
	n = 57		n = 57	
	Mean	(SD)	Mean	(SD)
Duration of compulsion				
No. of months of CTO treatment[1]	14.8	(14.4)	6.3	(10.5)
No. of months of involuntary hospitalisation[2]	6.0	(6.2)	6.7	(7.9)
No. of months of all compulsion (community and hospital)	20.8	(15.4)	13.0	(12.7)
Social Inclusion (SCOPE)				
Satisfaction with Opportunities	4.3	(0.9)	4.5	(1.0)
Perceived Opportunities	3.1	(0.7)	3.2	(0.8)
Perceived social inclusion[3]	4.4	(1.6)	4.4	(1.6)

[1] *Multiple periods on CTO included;* [2] *Includes index admission;* [3] *Response to the question: 'Overall, how do you feel about the extent to which you are included in society?'*

Patients in the CTO group had marginally lower Satisfaction with Opportunities scores compared to the Control group (4.32 vs. 4.48), while the difference for Perceived Opportunities was even smaller (3.13 vs. 3.16), and there was no difference in patients' subjective perceptions of their own social inclusion.

Table 15 shows the SCOPE sub-scales stratified by gender, age and ethnicity. Patients in the 'Other' ethnic groups had significantly higher Satisfaction with Opportunities scores than patients in the 'White' ethnic group ($t = -2.04$, $p < .05$). There were no between-group differences for patients' Perceived Opportunities scores. Likewise,

there were no between-group differences in Satisfaction with Opportunities, Perceived Opportunities and Perceived social inclusion scores for either gender or ethnicity.

Table 15 Social inclusion measured by SCOPE for psychosis patients (n = 114) at 48-month follow-up by gender, age and ethnicity

	Gender				**Age**				**Ethnicity**			
	Male		**Female**		**<40 years**		**≥40 years**		**White**		**Other**	
	n = 76		**n = 38**		**n = 59**		**n = 55**		**n = 56**		**n = 58**	
	Mean	**(SD)**	**Mean**	**(SD)**	**Mean**	**(SD)**	**Mean**	**(SD)**	**Mean**	**(SD)**	**Mean**	**(SD)**
Satisfaction with Opportunities	4.5	(0.8)	4.3	(1.1)	4.5	(0.9)	4.3	(1.0)	4.2*	(0.9)	4.6*	(0.9)
Perceived Opportunities	3.2	(0.8)	3.1	(0.8)	3.2	(0.7)	3.1	(0.8)	3.1	(0.8)	3.2	(0.7)
Perceived social inclusion[1]	4.4	(1.6)	4.3	(1.5)	4.5	(1.4)	4.4	(1.8)	4.4	(1.5)	4.3	(1.6)

SCOPE = Social and Community Opportunities Profile; [1] *Response to the question: 'Overall, how do you feel about the extent to which you are included in society?';* * *Significant at the .05 level.*

Mean scores for the SCOPE sub-scales are presented in **Table 16** together with data for two mental health samples and the general population obtained from Huxley et al. (2012). There is no clear pattern in the data across the four groups. Patients with psychotic illnesses were slightly less satisfied with their opportunities for social inclusion compared to the Mental Health Controls (healthy controls) (4.4 vs. 5.0) although their perception of opportunities was roughly the same (3.1 vs. 3.2). The psychosis sample showed slightly higher levels of Satisfaction with Opportunities and perception of opportunities, when compared with the Common Mental Disorders group. There was almost no difference in scores between the psychosis sample and the Mental Health Service User group. None of the observed differences were statistically significant.

Table 16 Mean scores for SCOPE sub-scales for different patient groups and a group of healthy controls

	OCTET Social Outcomes Study		**Mental Health Service Users[1,2]**		**Common Mental Disorders[1]**		**Mental Health Controls[1]**	
	n = 114		**n = 43**		**n = 40**		**n = 212**	
	Mean	**SD**	**Mean**	**SD**	**Mean**	**SD**	**Mean**	**SD**
Satisfaction with Opportunities	4.4	(1.0)	4.5	(0.87)	4.2	(0.92)	5.0	(0.76)
Perceived Opportunities	3.1	(0.71)	2.9	(0.81)	2.5	(1.0)	3.2	(1.0)

[1] *Huxley et al. (2012);* [2] *Severe and chronic mental health problems (Huxley et al., 2012)*

Objective indicators of social inclusion, including comparisons with a Mental Health Service User group and national survey data, are presented in **Tables 17** and **18**. Data in these tables show that patients with psychotic illnesses had similar levels of social inclusion compared to the Mental Health Service User group but had, on average, lower levels of inclusion when compared with figures for the general population obtained from UK national survey data (Huxley et al., 2012).

Table 17 SCOPE objective social inclusion indicators for the general population, patients with severe mental illness and psychosis patients

Item		Survey source	Survey Result	Mental Health Service Users[1] (n = 43)	OCTET Social Outcomes Study (n = 114)
Been a victim of crime		*British Crime Survey (2008)*	7%	13%	15%
In paid employment		*British Household Panel Survey (2007)*	50%	8%	6%
Get income from paid employment / pension		*Health Survey for England (2006)*	73%	9%	8%
Able to borrow small sum of money if needed		*Resource Generator UK (2007)*	89%	90%	78%
Qualified to A level or above		*General Household Survey (2009)*	35%	32%	32%
No. of friends	0	*Citizenship Survey ('People, Families and Communities')(2008)*	7.2%	NA	11%
	1-9		84%	61%	68%
	10+		5.3%	39%	21%

[1] *Severe and chronic mental health problems (Huxley et al., 2012); NA = not available*

Table 18 SCOPE objective indicators of participation for the general population, patients with severe mental illness and psychosis patients

Item	Survey source	Survey Result	Mental Health Service Users[1] (n = 43)	OCTET Social Outcomes Study (n = 114)
Voted in last general election	*British Household Panel Survey (2009)*	59%	72%	40%
Been in education in past 12 months (p/t or f/t)	*Family and Children Survey (2007)*	27%	16%	16%
At least annual contact with parents	*Home Office Citizenship Survey (2001)*	NA (modified question)	94%	93%
Friends visit at least weekly	*Home Office Citizenship Survey (2001)*	NA (modified question)	23%	34%

[1] *Severe and chronic mental health problems (Huxley et al., 2012);* *NA = not available*

3.5 Discussion

3.5.1 Main findings

This is the first study to test the association between the duration of community and hospital compulsion and social inclusion using a formally developed social inclusion measure. It found no significant association between the total number of months of CTO treatment over 48-months and patients' level of social inclusion at follow-up. This result was unchanged even when the number of months on CTO was calculated as proportion of months spent in the community. Additionally, there was no significant association between the duration of CTO treatment and objective indicators of social inclusion as measured by the Objective Social Outcomes Index (SIX).

This latter finding is consistent with evidence from a published secondary analysis of the OCTET Trial data which found no effect of community compulsion on patients' SIX scores at 12-months follow-up (Rugkåsa et al., 2014b). Likewise, a small qualitative study (n = 9) found that CTOs did not improve patients' access to employment, education, training or recreational activities or help to reduce patients' perceptions of stigma and discrimination (Taylor et al., 2013), although this study did not assess actual change but was based on the views of Approved Mental Health Professionals. There appears to be little association between community compulsion and objective indicators of social inclusion, in the short-term or long-term, although the number of published studies in this area remains small.

3.5.2 Subsidiary findings

There was also no significant association between the durations of involuntary hospitalisation and patients' social inclusion at follow-up, or between the durations of *any* legal compulsion (i.e. CTO treatment and involuntary hospitalisation) and patients' social inclusion at follow-up. Likewise, there were no significant differences in patient scores on the SCOPE's sub-scales or the subjective perceived social inclusion question, when stratified by original arm of randomisation: whether patients were randomised to CTO or the Control group at baseline had no effect on subjective self-reported social inclusion four years later. This is unsurprising given the cross-overs between the CTO and Control arms that occurred at baseline and during the first year of the OCTET Trial (Burns et al. 2013), and because of the long duration of follow-up thereafter, which would have further 'diluted' the effects of randomisation (see Discussion, *Chapter 2*).

There was some evidence that satisfaction with opportunities (measured by the Satisfaction with Opportunities sub-scale) was higher for patients in the 'Other' ethnic group than those in the White group. This result is perhaps surprising since one might expect ethnic minorities to be more unsatisfied with their opportunities compared with the majority white population. The finding can be contrasted with evidence from a number of studies showing that in the UK and many other countries ethnic minorities experience considerable disadvantage in many areas of life, including employment, education, social capital and health (Bates, 2005; Evandrou, 2000; Levitas et al., 2007; Sproston and Mindell, 2006). These disadvantages are likely to shape the expectations of minority groups in important ways. For example, it is possible that persistent disadvantage leads to a lowering of expectations about the

choices and opportunities available, with the result that ethnic minorities report higher levels of subjective satisfaction when compared with the general population, as found in this study. One possible consequence of these lowered expectations is that they reinforce the cycle disadvantage by stifling individual aspiration.

3.5.3 Comparisons with previous studies and the general population

There was little difference in scores on the subjective indicators of social inclusion (satisfaction with opportunities and perceived opportunities) when patients in this study were compared with other patient groups and healthy controls (Huxley et al., 2012) (**Table 14**). However, patients in this study scored lower on average on nearly all objective indicators of social inclusion when compared with the mental health service user group (**Table 15** and **16**). None of these differences were statistically significant, and Huxley et al.'s (2012) patient samples are relatively small, so these results should be interpreted with caution. (Patients in Huxley et al.'s sample were also slightly older [mean = 49 years, SD = 12], made up of a greater proportion of females [56%], and of mixed but unspecified diagnoses – described as a sample with "severe mental health problems".) The low levels of inclusion captured by objective indicators in the present study are broadly consistent with previous research showing poor social inclusion among patients with severe mental illness when compared with the general population (Huxley et al., 2003; Killaspy et al., 2014; Social Exclusion Unit, 2004).

3.5.4 *Strengths and limitations*

The regression analyses in this study all produced relatively small beta coefficients (none were larger than 0.01) with small confidence intervals. The small beta values show that there was little association between the predictor and outcome and the small confidence intervals (distributed around zero) indicate a high degree of confidence in this result (Higgins and Green, 2011). Small confidence intervals can arise as a result of limited variance in the study population, however, this is unlikely to explain the results found here because some variance was evident in both in the predictor and outcome variables used in the analysis. This suggests that the beta coefficients observed in this study are unlikely to have arisen from a lack of statistical power due to limited sample size but reflect instead a genuine absence of relationship between compulsion and social inclusion.

An important limitation of Study 2 was the failure to control for social inclusion at baseline. Adjusting for baseline covariates reduces the likelihood of differences in exposure to the predictor of interest (Glymour et al., 2005) in this case the duration of CTO treatment. Although an individual's degree of social inclusion is not a known risk factor for being placed on a CTO, there is at least the possibility that patients who were less socially included following the first year of the study were more likely to be placed on a CTO. For example, a clinician might believe that the patient's lack of social support would lead to poor adherence with treatment but, if placed on a CTO, the additional structure and support provided by the intervention should increase their adherence with treatment and therefore reduce relapse. The possibility that this occurred at baseline was low due to the largely successful randomisation process; however, a bias may have been introduced following the first year of the study when

patients who were not randomised to the CTO arm were subsequently placed on CTOs. While this limitation is important to recognise in theory, it is of limited practical relevance when interpreting these results because there was no significant association between the duration of compulsion and social inclusion, in either the adjusted or the unadjusted regression models. Controlling for a covariate can attenuate the strength of a significant association between a predictor and outcome variable by accounting for some of the variance, but it will not increase the p-value of a non-significant association (Field, 2013).

These limitations, including the more general limitation of correlational research, which also apply to Studies 1 and 3, are discussed under the sub-heading *General limitations of the OCTET Social Outcomes Study* in the Discussion of *Chapter 2*.

Limitations of the SCOPE

The SCOPE is one of a small handful of social inclusion measures designed for use in a mental health context. Reviews of the literature suggest that the SCOPE is the most robust measure of social inclusion developed to date, although further evaluation and testing of the instrument, including with other patient groups, has been called for (Baumgartner and Burns, 2014; Coombes et al., 2013; Huxley et al., 2012). To this end, a critical evaluation of the instrument's performance in a clinical research setting was carried out, including evaluation of its feasibility, reliability and validity, and is the subject of *Chapter 5*. Note that the main limitation of the SCOPE identified in *Chapter 5* was the internal consistency of the Perceived Opportunities sub-scale, which was found to be poor, raising questions about the instrument's reliability. The results of Study 3 should be interpreted with this limitation in mind.

3.5.5 Summary

This study used regression analyses to test whether the duration of CTO treatment was associated with more or less favourable social inclusion outcomes at 48-months follow-up. No association was found. There was also no significant association observed between the duration of involuntary hospitalisation and patients' social inclusion at follow-up. This study casts doubt on CTO effectiveness to improve social outcomes for patients. These findings require further validation in larger, controlled, long-term trials with explicitly designed social inclusion measures.

Chapter 4: Capabilities and psychiatric compulsion

The identity of an individual is essentially a function of her choices, rather than the discovery of an immutable attribute

– Amartya Sen

4.1 Introduction

4.1.1 The capability approach

The capability approach has been one of the most important and influential contributions to the understanding of human welfare in the past forty years. First pioneered by the economist, political philosopher and Nobel Laureate Amartya Sen (1979; 1993; 1999a; 1999b), the capability approach provides a normative framework for the conceptualisation and evaluation of individual well-being and social arrangements. The approach has been applied in a wide variety of disciplines including international development, political philosophy, welfare economics, social policy and healthcare (Coast et al., 2014; Robeyns, 2005) and has also been highly influential in development economics where it led to the introduction of the Human Development Index (United Nations Development Programme, 1990).

According to Sen (1993), well-being should be conceptualised in terms of peoples' ability to function – that is for people to *be* and *do* the things that matter to them and that they have reason to value. These *functionings* can range from the rudimentary, such as being adequately nourished and housed to the more abstract, such as feeling

socially valued or achieving self-respect. It is these 'beings' and 'doings', Sen argues, that make life valuable to the individual and worth living (Sen, 1993).

Capabilities refer to the different combinations of functionings that an individual can feasibly choose from. Sen distinguishes between functionings – what I do or am – and capabilities – what I am *able* or *free* to do or be (Sen, 1993). The distinction between achieved functionings and capabilities is between that which is realised and that which is effectively possible (Robeyns, 2005). Sen (1993) illustrates this distinction with the example of a person who is starving and a person who is fasting. In both cases, the functional outcome is the same – they don't eat – but their capabilities are different: the first person does not have the capability to eat while the second person does, but chooses not to exercise it. What matters for well-being, then, is not what functionings an individual has achieved, but rather the genuine opportunities to achieve the functionings that matter to that individual.

The capability approach has generated considerable recent interest among health economists and social scientists as a framework for assessing human welfare in the context of health and social policy evaluation (Anand et al., 2005; Anand, 2005a; 2005b; Coast et al., 2008b; Coast et al., 2008c; Francis and Byford, 2011; Lorgelly et al., 2010; Verkerk et al., 2001). One recognised advantage of the approach is that well-being is not reduced to resource-based evaluations or subjective states typical of many standard welfare approaches (Lorgelly et al., 2010). Sen rejects utilitarian approaches to welfare that rely exclusively on the material means to well-being (such as income or wealth) or subjective categories (such as happiness or desire fulfilment). He does not argue that resources or subjective ratings are unimportant; rather, it is the

exclusive focus on them that is problematic and leads to an incomplete and unreliable measure of human welfare (Sen, 1993).

Growing interest in the capability framework has led to several attempts to operationalise the approach and a number of novel health outcome measures have emerged (see Coast et al., 2014). This chapter introduces the capability approach and its use in health economics, the development and early testing of the OxCAP-MH – a new capability measure developed for use in mental health research – and its application as a social outcome measure in the OCTET Social Outcomes Study (Study 3).

4.1.2 Patient reported outcome measures

Standardised outcome assessment is widely used in general and mental healthcare to evaluate health and social care interventions and to aid decisions about resource allocation. Traditionally, such assessments have focused on clinicians' ratings and judgement with only limited attention given to the point of view of the patient. In recent decades there has been increasing recognition that information from the patient's perspective is essential to capturing the full range of health and non-health life domains that can be impacted by illness or an intervention (Devlin and Appleby, 2010). This has led to a growing emphasis on the use of patient reported outcomes measures (PROMs) with the aim of improving outcome measurement accuracy and increasing patient involvement and satisfaction (Black, 2013). It has recently been argued that the use of patient rated measures should be the primary approach to evaluating outcomes of mental health interventions (Thornicroft and Slade, 2014).

The purpose of a PROM is to assess, from the patient's perspective, the impact of illness or an intervention on their life – be that physical functioning, well-being, health-related quality of life, capabilities, or some other measure of outcome (Nelson et al., 2015). Several studies have shown that the systematic use of information generated from PROMs can improve decision making and communication between doctors and patients and increase patient satisfaction with care (Chen et al., 2013; Marshall et al., 2006; Santana and Feeny, 2014; Valderas et al., 2008; Wasson et al., 1999). There is also evidence that data obtained from PROMs can be used to improve outcomes in certain psychiatric conditions such as depression (Ahles et al., 2006). PROMs are widely and increasingly used within the National Health Service in the United Kingdom and called for by clinicians, researchers and other stakeholders groups (Black, 2013; Devlin and Appleby, 2010; NICE, 2008).

Like all outcome measures, PROMs can be either disease-specific or generic. *Disease-specific* instruments focus on specific conditions, diseases or aspects of health. G*eneric* instruments can be used with different patients with different conditions so that health outcomes can be compared across different patient and population groups (Devlin and Appleby, 2010). Generic measures typically focus on the impact of a certain health state or condition on the patient's ability to function and enjoy life, frequently referred to as health-related quality of life measures.

The EQ-5D is the most widely used generic health-related quality of life PROM in the United Kingdom and Europe (Brooks, 1996; EuroQol-Group, 1990; Lorgelly et al., 2010). The instrument is endorsed by the National Institute for Health and Clinical Excellence (NICE) for the calculation of quality adjusted life years (QALY) used in cost-utility analyses (Brooks, 1996; EuroQol-Group, 1990; NICE, 2013). The EQ-5D is

widely used in general and mental health contexts but has been criticised on methodological and conceptual grounds (Brazier, 2010; Janssen et al., 2013). First, the instrument focuses exclusively on health-related quality of life and consequently fails to capture non-health benefits and broader welfare inequalities and, second, it has been shown to lack sensitivity when applied to mental health populations, particularly those with psychotic disorders and severe and complex non-psychotic disorders (Brazier, 2010).

4.1.3 Applications of the capability framework

There is growing consensus among health economists, social scientists and policy makers that the capability approach offers a richer, more nuanced theoretical evaluative space for welfare assessment when compared with traditional utilitarian welfare approaches, which provide the theoretical underpinnings of measures such as the EQ-5D (Anand, 2005a; 2005b; Coast et al., 2008a; 2008b; Francis and Byford, 2011; Lorgelly et al., 2010; Verkerk et al., 2001). A major strength of the capability approach is that it is inherently multi-dimensional and therefore shifts the focus of measurement towards a broader set of outcomes (Coast et al., 2014). This is relevant for health and social policy evaluations in which both health and non-health outcomes are known to matter – such as in a mental health context. For people with mental health problems, health is likely to represent one of a wide range of relevant outcomes; other relevant outcomes might include whether someone has a job, housing and social relationships, all of which can directly or indirectly impact on health outcomes. Multi-dimensional approaches to welfare assessment will, by

definition, capture a wider range of domains that might be impacted, when compared with unidimensional approaches.

Operationalising the capability approach

Attempts to operationalise the capability approach and create a viable measure have encountered a number of obstacles. Chief among these is the problem of deciding on a definitive list of capabilities. Should there be a single capabilities list for use in all contexts or does each context require a different list? Should selection use participatory methods or be expert-led? There is still no accepted best-practice approach for selecting specific capabilities (for a recent discussion of methodological and measurement challenges, see Coast et al., 2014; Robeyns, 2005). Sen himself declined to provide an authoritative capabilities list arguing that that such a list should arise out of democratic process – or "reasoned consensus" – among those who intend to use the list (Sen, 1999, p.78). Whether such a democratic process is feasible has been the subject of some contention (e.g. Robeyns, 2003; 2005). The political philosopher Martha Nussbaum has produced the most widely accepted list which includes the ten central human capabilities (Internet Encyclopedia of Philosophy, 2015; Nussbaum, 2003):

1. ***Life*** – Able to live life to its normal end, and to not have it reduced to a life not worth living.
2. ***Bodily health*** – Able to have a good life including – but not limited to – reproductive health, nourishment and shelter.
3. ***Bodily integrity*** – Able to move freely between locations, in addition to having sovereignty over one's body, including freedom from assault.

4. ***Senses, imagination and thought*** – Able to use one's senses to imagine, think and reason in a 'truly human way', informed by adequate education. The ability to have pleasurable experiences and avoid unnecessary pain. To have freedom of religion and religious expression, and to search for meaning in life.
5. ***Emotions*** – Able to have attachments to things and people outside of ourselves, including being able to love others, grieve at loss or to be angry when it is justified.
6. ***Practical reason*** - Able to form a conception of the good and critically reflect on it.
7. ***Affiliation*** – (1) Able to live with and show concern for others, empathize with (and show compassion for) others and the capability of justice and friendship. (2) Able to have self-respect and not be humiliated by others; to be treated with dignity and equal worth. This includes (at the very least) protections against being discriminated on the basis of race, sex, sexuality, religion, caste, ethnicity and nationality.
8. ***Other species*** – Able to have concern for and live with other animals, plants and the world of nature.
9. ***Play*** – Able to laugh, play and enjoy recreational activities.
10. ***Control over one's environment*** – (1) *Political*: Able to effectively participate in political life which includes having the right to free speech and association. (2) *Material*: Able to own property and goods without fear of unwarranted search and seizure, and able to seek employment on an equal basis with others.

Although Nussbaum's list is the most widely accepted, several other lists have emerged, most of which are highly generic and contain considerable conceptual overlap with one another (Alkire, 2005).

Capability measures

There has been substantial progress over the past decade in the development of new capability measures. Coast and colleagues (2014) identify three main groups of capability measures: the Adult Social Care Outcomes Toolkit (ASCOT) (Netten et al., 2002; 2012), the ICEpop CAPability instruments (ICECAP) (Al-Janabi et al., 2012; Coast et al., 2008a; Flynn et al., 2015; Grewal et al., 2006) and the Oxford Capability instruments (OxCAP) (Anand et al., 2009; Lorgelly et al., 2008; Simon et al., 2013; Vergunst et al., 2014). The ASCOT and ICECAP instruments were both originally developed with the aim of capturing capabilities specifically in relation to social care, while the OxCAP instruments (Anand et al., 2009; Lorgelly et al., 2008) were developed for public health assessments and later adapted for use in a mental health context, such as the OxCAP-MH (Simon et al., 2013).

The OxCAP-MH

The OxCAP-MH programme of research was the first attempt to apply the capability framework to outcome measurement in a mental health context (Simon et al., 2013; Vergunst et al., 2014). The work builds on earlier work by Anand and colleagues (2009) who, guided by Nussbaum's (2003) list of ten essential capabilities, identified direct measures of capabilities from large population survey data, resulting in a 64-item

questionnaire. Anand et al.'s work was further developed by Lorgelly and colleagues (2008) who modified the list using focus groups, factor analysis, pilot questionnaires and interviews to produce a shorter more practical 18-item capabilities list that could be used in public health assessments. The OxCAP-MH further refined Lorgelly et al.'s 18-item list, adapting it for use in a mental health context through discussion with psychiatrists, clinical psychologists, social scientists and health economists. The OxCAP-MH was piloted for feasibility, acceptability and content validity with a sub-sample of patients with psychotic illnesses (n = 20) before full testing within the OCTET Trial (Simon et al., 2013). A comprehensive discussion of the development of the OxCAP-MH is described by Simon et al. (2013).

The final version of the OxCAP-MH contains 16-items and covers multiple capability domains relevant to people with mental illness (Simon et al., 2013) (for the precise wording of questions, see *Appendix I*, Section 7). These domains are:

- Daily activities
- Social networks
- Losing sleep
- Enjoying recreational activities
- Suitable accommodation
- Neighbourhood safety
- Discrimination
- Potential for assault
- Influence local decisions
- Freedom of expression
- Appreciation of nature

- Respecting and valuing people
- Love friendship and support
- Planning one's life / self-determination
- Imagination and creativity
- Access to meaningful activities

Initial testing of OxCAP-MH supported the feasibility and face validity of directly measuring capabilities in patients with severe mental illness (Simon et al., 2013). More recent work, reported in Chapter 6, indicates that the instrument has good psychometric properties in terms of reliability and validity (Vergunst et al., 2014).

4.1.4 Psychiatric compulsion and capabilities (Study 3)

The use of psychiatric compulsion represents a substantial infringement on an individual's civil liberties. In addition to a physical loss of freedom (e.g. freedom of movement and association), such treatment could lead to a psychological loss of freedom (induced by experiences of fear, helplessness, loss of dignity, humiliation and stigma) to be and do things that are of value to the individual. To date, there have been few, if any, empirical tests of the relationship between compulsory interventions and individual freedom to achieve valued functionings. Study 3 used the OxCAP-MH, a multi-dimensional patient-rated capabilities measure, to test the association between the duration of compulsion (CTO and involuntary hospitalisation) and patients' freedom to achieve valued functionings across a range of capabilities domains.

The rationale for testing the association between compulsion and social outcomes more broadly can be found in *Chapter 1* under the sub-heading *1.5.3 Study rationale and hypotheses*.

4.2 Research questions

Principal questions

1. Is a longer duration of CTO treatment over 48-months associated with patients' capabilities at follow-up?
2. Is a longer duration of CTO treatment over 48-months, calculated as a *proportion* of time spent in the community, associated with patients' capabilities at follow-up?

Subsidiary questions

1. Is a longer duration of involuntary hospitalisation over 48-months associated with patients' capabilities at follow-up?
2. Is a longer duration of *any* legal compulsion (hospital and community) over 48-months associated with patients' capabilities at follow-up?
3. Are there between-group differences in patients' capabilities and health-related quality of life when stratified by arm of randomisation (CTO vs. Control)?

4. Is gender (Male vs. Female), age (<40 years vs. ≥40 years) or ethnicity (White vs. Other) associated with patient-reported capabilities and health-related quality?

4.3 Methods

Unless indicated otherwise, the sample, design, procedure, and data management used in Study 3 are the same as those used in Study 1, *Chapter 2*.

4.3.1 Instruments used in the study

Capabilities: *The Oxford Capability Questionnaire for Mental Health (OxCAP-MH)* (Simon et al., 2013) is a 16-item self-complete or researcher/clinician-assisted questionnaire covering multiple capability domains. The instrument is scored on a five-point Likert scale (strongly agree, agree, neither agree nor disagree, disagree, strongly disagree) with higher scores indicating better capabilities. Items are summed and converted into a standardised 0-100 scale for each patient using the formula: 100 × (OxCAP-MH total score – minimum score)/range. The instrument has good feasibility and face validity but further testing of the instrument's psychometric properties is required (Simon et al., 2013; Vergunst et al., 2014). Full validation of the instrument in terms of reliability, validity and sensitivity to change is the subject of *Chapter 6*. The OxCAP-MH is described in further detail in the Methods section of *Chapter 6* (p.183).

Health-related quality of life: *EuroQol EQ-5D* (EuroQol-Group, 1990; Glick, 1999). See Methods section of the Social network study, *Chapter 2* (p.53).

Psychopathology: *The Brief Psychiatric Rating Scale (BPRS)* (Mortimer, 2007; Overall and Gorham, 1962). See Methods section of the Social network study, *Chapter 2* (p.53).

Perceived coercion: *Admission Experience Survey (AES)* (Gardner et al., 1993). See Methods section of the Social network study, *Chapter 2* (p.54).

Instruments used in this study sample are reproduced in full in *Appendix I*.

4.3.2 Statistical analyses

Data were tested for normality using the one-sample Kolmogorov-Smirnov test of goodness of fit. Descriptive statistics were reported using means (SD) and between-group comparisons used t-tests. Imputation methods for missing data were considered but found unfeasible given the non-random nature of the missing data (Field, 2013).

Principal analyses

Multiple linear regression analyses were used to test for an association between the total days of CTO treatment (which includes multiple periods of CTO treatment) during follow-up and patients' total capability scores as measured by the OxCAP-MH. This analysis was repeated for the second principal question using the *total duration of CTO treatment calculated as a proportion of days spent in the community* as the

main predictor. Both analyses controlled for the following factors: age, gender, duration of illness, diagnosis (schizophrenia vs. other), illness severity (total days in hospital during follow-up), and perceived coercion at follow-up. Because depression has been shown to strongly influence subjective quality of life ratings (Kaiser et al., 1997; Newton-Howes, 2014; Priebe et al., 2000), it was controlled for in all regression analyses using BPRS depression scores collected at the 48-month follow-up interview.

To facilitate interpretation of the regression analyses, the main predictors (total number of days on a CTO and number of days of involuntary hospitalisation) were converted into months by dividing the total number of days of compulsion for each patient by 30.43 prior to analysis. This reduced the number of decimal places in the beta coefficients making the ratio between the predictor and outcome easier to interpret.

Sensitivity analyses

Due to missing data, baseline OxCAP-MH scores could not be controlled for in the main regression analyses without a substantial reduction in sample size and therefore loss of power. Consequently, a separate sensitivity analysis of the principal outcomes was carried out in which baseline OxCAP-MH scores were added to the regression model in addition to the existing covariates described above. A second sensitivity analysis was also conducted in which only patients who had been subjected to CTO treatment during follow-up were included (n = 70). This analysis was carried out for the principal questions only.

Subsidiary analyses

The linear regression models used above were applied to the first and second subsidiary questions, but replacing the main predictors with the *total number of months of involuntary hospitalisation* and *total number of months of any compulsion (hospital and community)* respectively. Patients' capabilities (OxCAP-MH total scores) and health-related quality of life as measured by the widely used EQ-5D (Brooks, 1996) were examined based on patients' allocated treatment arm at baseline (CTO vs. Control). Patients' OxCAP-MH scores were also examined by gender (Male vs. Female), age (<40 years vs. ≥40 years) and ethnicity (White vs. Other). Independent samples t-tests were used to test for significant between-group differences.

4.4 Results

Participant flow and follow-up is described in the Results of Study 1, *Chapter 2* (p.60). Complete social inclusion data were available for 114 patients and all analyses were carried out on this sample. The socio-demographic and clinical characteristics of the sample are presented in Study 1, *Chapter 2* (see Table 1, p.62). Interventions and changes in legal status during 48-month follow-up are presented in **Table 2**, *Chapter 2* (p.65).

As in Study 1, cases that did not have complete data for the outcome and all predictors were dropped from the regression analyses. Of the 114 patients included in the OCTET Social Outcomes Study, nine were removed because of missing data for the AES-PC

(the AES-PC was used to control for perceived coercion at follow-up but could not be completed by patients who had been discharged from mental health services since the instrument asks about pressure/coercion in relation to their care coordinator and CMHT experienced in the last six months). One further patient was dropped because their duration of illness was unknown. All regression analyses were consequently conducted on a sample of 104 patients.

4.4.1 Principal findings

No association was found between the duration of CTO treatment over the 48-months of study and patients' capabilities scores at follow-up (B = 0.046, p = ns) (95% CI = -0.07 – 0.16) (**Table 19**). Patients' depression scores at 48-months follow-up were significantly associated with capabilities scores (B = -2.301, p < .001) (95% CI = -3.30 – -1.302) such that for every unit increase in depression (as measured by the BPRS) there was a corresponding decrease in of 2.3 points in capabilities, holding all other variables constant. Perceived coercion was also significantly associated with patients' capabilities such that for every point increase on the perceived coercion scale there was a corresponding decrease in of 0.4 points on the OxCAP-MH (B = -0.405, p < .05) (95% CI = -0.759 – -0.050), holding all other variables constant. In the second principal regression analysis, no significant association was found when the duration of compulsion was calculated as a proportion of time spent in the community during follow-up (B = 0.051, p = ns) (95% CI = -0.03 – 0.16) although, again, depression and perceived coercion were significantly associated with patients' OxCAP-MH scores. For both analyses the beta coefficients were small and the confidence intervals narrow.

Table 19 Multiple linear regression testing the association between the number of months of CTO treatment over 48-month and OxCAP-MH scores at follow-up

				95% confidence interval for B	
Predictors[1]	**B**	**SEB**	**p**	**Lower**	**Upper**
Constant	65.0				
No. of months of CTO treatment	0.046	0.056	0.410	-0.065	0.157
Depression at 48-months	-2.301	0.503	0.001	-3.300	-1.302
Perceived coercion at 48-months	-0.405	0.179	0.026	-0.759	-0.050
R^2 = 0.30					
Constant	68.14				
No. of months of CTO treatment calculated as a proportion of months in the community	0.051	0.049	0.299	-0.046	0.149
Depression at 48-months	-2.323	0.502	0.000	-3.320	-1.326
Perceived coercion at 48-months	-0.412	0.178	0.023	-0.766	-0.058
R^2 = 0.27					

[1] *Controlling for age, gender, duration of illness, diagnosis, illness severity (days in hospital during follow-up), perceived coercion and depression at follow-up*

Sensitivity analyses

There were 66 patients with complete baseline and 48-months follow-up data for all variables used in the regression analysis. Controlling for baseline capabilities, the regression analysis found no significant association between the duration of compulsion and patients' capabilities at follow-up (B = -0.008, p = ns, R^2 = 0.41) (95% CI = -0.138 – 0.122).

Of the 70 patients who had been subjected to CTO treatment during the 48-months follow-up included in the second sensitivity analysis, five were removed due to

missing perceived coercion data, leaving 65 in the analysis. There was no significant association between the duration of compulsion and patients' capabilities at 48-months follow-up (B = -0.108, p = 0.185, R^2 = 0.30) (95% CI = -0.053 – 0.269).

In both the sensitivity analyses, as in the principal analyses, depression and perceived coercion at 48-months follow-up were both significantly negatively associated with patients' capabilities scores.

4.4.2 Subsidiary findings

Table 20 shows that there was also no significant association between the duration of involuntary hospitalisation and patients' capabilities at follow-up (B = -0.128, p = ns) (95% CI = -0.609 – 0.353). Likewise, there was no significant association between the number of months of any legal compulsion (hospital and community) and capabilities scores at 48-months follow-up (B = 0.041, p = ns) (95% CI = -0.072 – 0.154). In both analyses, as described above, depression and perceived coercion at 48-months follow-up were significantly negatively associated with patients' OxCAP-MH scores.

Table 20 Multiple linear regression testing for association between the number of months of any legal compulsion during 48-month follow-up and patient capabilities

				95% confidence interval for B	
Predictors[1]	**B**	**SEB**	**p**	**Lower**	**Upper**
Constant	65.21				
No. of months of involuntary hospitalisation	-0.128	0.242	0.598	-0.609	0.353
Depression at 48-months	-2.268	0.511	0.001	-3.284	-1.1253
Perceived coercion at 48-months	-0.380	0.176	0.034	-0.730	-0.030
R^2 = 0.30					
Constant	64.90				
No. of months of any legal compulsion	0.041	0.057	0.475	-0.072	0.154
Depression at 48-months	-2.317	0.504	0.001	-3.317	-1.317
Perceived coercion at 48-months	-0.401	0.179	0.027	-0.756	-0.046
R^2 = 0.30					

[1] *Controlling for age, gender, duration of illness, diagnosis, illness severity (days in hospital during follow-up), perceived coercion and depression at follow-up*

For both principal and subsidiary regression analyses, gender approached but did not reach statistical significance (p values ranged from .056 to .091). In all four regression analyses (principal and subsidiary), for every unit increase in female gender there was a corresponding decrease in capabilities scores, holding all other variables constant. In other words, being female was associated with lower capabilities when compared with being male. This observation should be cautiously interpreted of course because gender did not actually reach statistical significance in the regression analyses; however, it is consistent with results presented in **Table 22** in which capabilities, stratified by gender, were significantly lower for females than for males.

Table 21 shows that patients randomised to the CTO arm of the OCTET Trial were subjected to a mean of 14.8 (SD = 14.4) months of compulsion during the 48-months follow-up compared to 6.3 (10.5) in the Control arm. There were no significant differences in OxCAP-MH (62 vs. 59) or EQ-5D scores at 48-months follow-up when stratified by arm of randomisation.

Table 21 Duration of compulsion and patient capabilities at 48-months by OCTET randomisation

	CTO		**Control**	
	n = 57		**n = 57**	
	Mean	**(SD)**	**Mean**	**(SD)**
Duration of compulsion				
No. of months of CTO treatment[1]	14.8	(14.4)	6.3	(10.5)
No. of months of involuntary hospitalisation2	6.0	(6.2)	6.7	(7.9)
No. of months of all compulsion (community and hospital)	20.8	(15.4)	13.0	(12.7)
Social outcome				
Capabilities (OxCAP-MH)	62.11	(8.97)	58.58	(8.94)
Health-related quality of life (EQ-5D Utilities)	0.73	0.31	0.67	(0.29)

[1] *Multiple periods of CTO included;* [2] *Includes index admission*

Table 22 shows the capabilities (OxCAP-MH) and health-related quality of life (EQ-5D) scores stratified by gender, age and ethnicity. Males had significantly higher mean capabilities scores than females (60 vs. 56) ($t = 2.60$, $p < .05$). Similarly, males had slightly higher health-related quality of life scores than females as measured by EQ-5D (0.72 vs. 0.66), although this differences was not statistically significant. Patients

aged <40 years had slightly higher capabilities scores compared with patients aged ≥40 years although, again, this difference was not statistically significant. There was no difference between capabilities scores when stratified by ethnicity.

Table 22 Capabilities and health-related quality of life for psychosis patients (n = 114) at 48-months follow-up by gender, age and ethnicity

	Gender				**Age**				**Ethnicity**			
	Male		**Female**		**<40 years**		**≥40 years**		**White**		**Other**	
	n = 76		**n = 38**		**n = 59**		**n = 55**		**n = 56**		**n = 58**	
	Mean	**(SD)**	**Mean**	**(SD)**	**Mean**	**(SD)**	**Mean**	**(SD)**	**Mean**	**(SD)**	**Mean**	**(SD)**
Capabilities (OxCAP-MH)	60.4*	(7.6)	56.2*	(9.3)	60.6	(8.2)	57.5	(8.4)	59.3	(8.4)	58.7	(8.4)
Health-related quality of life (EQ-5D Utilities)	0.72	(0.28)	0.66	(0.33)	0.70	(0.29)	0.69	(0.31)	0.66	(0.30)	0.73	(0.29)

** Significant at the .05 level*

4.5 Discussion

4.5.1 Principal findings

This study is the first to test the association between compulsion (CTO and involuntary hospitalisation) and patients' capabilities using a novel PROM developed for use in a mental health context. There was no significant association between the total number of months of CTO treatment over 48-months and patients' capabilities at follow-up. This result was unchanged when the number of months of CTO treatment was calculated as proportion of months spent in the community. There are currently no published studies with which to compare these findings although they are consistent with the results of Studies 1 and 2 which found no association between the duration of compulsion and social network size or social inclusion (see *Chapters 2* and *3*).

In the first sensitivity analysis, only patients who were subjected to CTO treatment during follow-up were included in the regression (n = 70), but this did not change the significance of the result. The beta coefficient and confidence intervals in this analysis was very close to the figures found for the full sample (**Table 19**). A second sensitivity analysis (n = 66 patients) was conducted in which baseline capabilities were controlled for but, again, this did not alter the significance of the result. Due to missing baseline data, both these analyses had reduced sample sizes, which may have resulted in a loss of power to detect a significant effect. However, the beta coefficients for these analyses were small and the confidence intervals narrow (as in the other regression analyses) which suggests that lack of power is an unlikely explanation for

the failure to detect an association (Higgins and Green, 2011). Additionally, changes in OxCAP-MH scores between baseline and 48-months for the full sample were on average small (mean = 0.52, SD = 10.5, median = 0.4, range = -22 – 29), which suggests further that controlling for baseline capabilities with a larger sample is unlikely to alter the result (see Discussion in *Chapter 3*).

4.5.2 Subsidiary findings

The subsidiary analyses found no significant association between the number of months that patients were subjected to involuntary hospitalisation and their capabilities at follow-up. Likewise, there was no significant association between all legal compulsion (hospital and community) during follow-up and patients' capabilities at 48-months. As in the principal analyses, the beta coefficients and confidence intervals were small in this analysis, suggesting a high degree of confidence in the finding that there is no association between involuntary hospitalisation and capabilities in the long-term (Higgins and Green, 2011).

There were no differences in patients' capabilities or health-related quality of life scores when they were stratified by arm of randomisation. As discussed in *Chapter 2* and *3*, this was unsurprising because the effects of the original randomisation were partially compromised by the protocol violations at baseline and because any effects are likely to have been considerably 'diluted' by the long follow-up duration (these limitations are discussed in more detail in the Discussion section of *Chapter 2*).

It is notable that in all regression analyses there was a significant negative association between patients' capabilities and perceived coercion scores. That is, higher perceived

coercion scores were associated with lower capabilities. This is perhaps unsurprising since capabilities are concerned with personal freedom – the freedom to be and do the things that we have reason to value – so one might expect that patients who perceive their care as more coercive will perceive their capabilities as more restricted. This is an encouraging finding and suggests that the OxCAP-MH is sensitive to individual perceptions of personal freedoms.

When capabilities and health-related quality of life were stratified by gender, age and ethnicity, the only significant between-group difference was for gender, with females having significantly lower capabilities scores than males. This is consistent with results from both the principal and subsidiary regression analyses in which female gender was significantly associated with lower OxCAP-MH scores at 48-months follow-up. These results also concur with baseline OCTET Trial data which showed that females had significantly lower overall capability scores compared to males (Simon et al., 2013). On individual capability domains, females scored significantly lower on 'having suitable accommodation' and 'neighbourhood safety' and significantly higher on 'potential for assault' (Simon et al., 2013). Thus, in this sample with psychotic illnesses, females appear to have lower self-reported capabilities than males and the discrepancy is also maintained over time.

These findings are also consistent with the broader capabilities literature in which a strong feminist tradition has repeatedly highlighted the barriers faced by women in achieving valued functionings (Nussbaum, 2000; 2001; 2003; Pyles, 2011; Robeyns, 2003; Sen, 1992a; 1999a). Women in much of the world continue to lack many of the fundamental functionings necessary for life (Nussbaum, 2000); compared to men, they are less likely to be adequately nourished, to have opportunities to be educated

or access to socially valued employment; in the workplace, they are more likely to face threats of violence and intimidation, discrimination in hiring decisions and sexual harassment (Nussbaum, 2000; United Nations Development Programme, 2014). Sen has argued that "the question of gender inequality . . . can be understood much better by comparing those things that intrinsically matter (such as functionings and capabilities), rather than just the means [to achieve them] like . . . resources. The issue of gender inequality is ultimately one of disparate freedoms" (Sen, 1992b, p.25). It is women, far more than men, who are affected by these disparate freedoms. Study 3 shows that in this sample with psychotic illnesses women are, again, more likely to be affected by these disparate freedoms.

In the context of outcome assessment, an important strength of the capability approach is that it offers a framework in which gender inequalities can be conceptualised and measured (Nussbaum, 2003). Sen himself did not provide explicit guidelines about which capabilities are relevant for assessing gender inequality although a list has subsequently emerged in the wider capabilities literature (Robeyns, 2003). One challenge for researchers wishing to operationalise the capabilities approach for outcome assessment is to ensure that the capabilities of both women and men are adequately represented in novel instruments. Identifying the specific capability domains in which women face particular barriers in achieving their valued functionings is essential for improving measurement accuracy. Once identified, these capability domains can be used to guide decisions about policy changes or the use of targeted interventions aimed at improving outcomes for women.

With respect to the gender differences in overall OxCAP-MH scores observed in Study 3, it is worth noting that men were slightly over represented in the study (67% of the

sample), and that the number of female participants was relatively small (n = 38), which may limit the generalisability of these results. Simon et al. (2013) observed a similar gender imbalance in their study although their overall sample was larger.

Compulsion and capabilities

Study 3 found no evidence of an association between the duration of CTO treatment and the extent to which patients feel they are able to be and do the things they value – their capabilities. This finding is consistent with Study 1 and 2 which found no association between the duration of CTO treatment and social network size and social inclusion. Taken together, the results suggest that in this sample of community based patients with psychotic illnesses, there is no association between the length of community compulsion and patients' long-term social outcomes. The failure to detect an association between compulsion and social outcomes is discussed in greater depth in *Chapter 7*.

Limitations

This study had a number of limitations some of which have been addressed above. The general limitations of the study shared with Studies 1 and 2 (such as the design, patient sample and follow-up procedure) are discussed under the heading *General limitations of the OCTET Social Outcomes Study* in *Chapter 2*. Limitations of the OxCAP-MH instrument are addressed in *Chapter 6*.

4.5.3 Summary

This chapter introduced the concept of capabilities, the recent application of the approach in health economics, and the development of a new capabilities measure for use in mental health research, the OxCAP-MH. Study 3 tested the association between the duration of CTO treatment over 48-months and patients' capabilities as measured by the OxCAP-MH at follow-up, finding no evidence of association. Similarly, no significant association between the duration of involuntary hospitalisation and patients' capabilities at follow-up was found. Subsidiary analyses revealed that females had significantly lower self-reported capabilities than males, a finding that is consistent with both theoretical and empirical literature. Taken together with Studies 1 and 2, this study casts further doubt on the effectiveness of CTOs and their capacity to improve social outcomes for patients in the long-term.

Chapter 5: A critical evaluation of the SCOPE

5.1 Introduction

5.1.1 Background

In this DPhil social inclusion was selected as one concept to capture social outcomes in the context of psychiatric compulsion. In recent years the concept has become increasingly topical among researchers, clinicians and policy makers although how it ought to be defined and measured remains contested (see the introduction to *Chapter 3*). Sustained calls for the development of a reliable and valid social inclusion measure for use in a mental health context have led to the development of several novel instruments but none of these have gained wide acceptance (Baumgartner and Burns, 2014; Morgan et al., 2007; Sayce, 2001). Among them, the Social and Community Opportunities Profile (SCOPE) has been identified as one of the most rigorously validated and overall promising instruments although further testing and validation have been called for (Baumgartner and Burns, 2014; Coombs et al., 2013; Huxley et al., 2012) (see Study 2).

This chapter describes the performance of the SCOPE in terms of its feasibility, content validity, and psychometric properties, in a clinical research setting with patients with psychotic illnesses.

5.1.2 The SCOPE

The SCOPE was developed in the UK as part of a Health Technology Assessment programme of the National Institute for Health Research to produce a reliable and valid measure of social inclusion for use in research and routine clinical practice with people with mental illness (Huxley et al., 2012). The instrument was originally developed in a longer version, containing 121 items, and later reduced using factor analysis to create the 48 item 'short version' (reference to the SCOPE is to the short version throughout). The SCOPE is comprised of

- Two sub-scales
  - Satisfaction with Opportunities *(8 items, 7-point Likert scales)*
  - Perceived Opportunities *(5 items, 5-point Likert scales)*
- A single question about the patient's subjective perception of their own social inclusion: 'Overall, how do you feel about the extent to which you are included in society?' *(1 item, 5-point Likert scale)*
- Objective indicators of social inclusion across multiple domains (e.g. accommodation, employment, education) *(34 items, various categorical scalings)*

The SCOPE is described in further detail in the *Instruments used in the study* section below and reproduced in full in *Appendix I*. A broader discussion about the conceptual background to social inclusion, including the development of the SCOPE, is given in *Chapter 3* and described in detail by Huxley and colleagues (2012).

Although recent reviews of the SCOPE have been favourable (Baumgartner and Burns, 2014; Coombs et al., 2013), the need for further testing and validation has been called for by the authors (Huxley et al., 2012) and others (Baumgartner and Burns, 2013, Coombs et al., 2013). Baumgartner and Burns (2014) note that the SCOPE has undergone more rigorous psychometric testing than the majority of available social inclusion measures but conclude that 'additional reliability and validity testing with different populations is warranted'. Similarly, Coombs and colleagues (2013) note in their review that the SCOPE's 'psychometric properties require further testing' (p.916), but make no more specific recommendations. The authors themselves advise further validation with larger samples of minority and disadvantaged groups, including those with physical illnesses and disabilities, and with specific mental health diagnostic groups, as well as further testing with individuals from different cultural backgrounds (Huxley et al., 2012). The instrument's sensitivity to change and responsiveness have yet to be established.

One further concern that might be raised about the SCOPE's psychometric properties is that patient samples used for validity testing were relatively small (43 patients with severe mental illness, 40 with common mental disorders), which raises questions about whether the results are representative and therefore generalizable. These sample sizes, from a statistical point of view, would be considered relatively small for the purposes of validity testing (e.g. Charter, 1999).

The aim of Study 4 was to critically evaluate the feasibility of the SCOPE, and the content validity, reliability and validity of its two sub-scales, in a clinical research setting with patients with psychotic illnesses.

5.2 Research questions

1. Is the SCOPE a feasible instrument for use in clinical research settings with patients with psychotic illnesses i.e. is it easy and brief to administer?
2. Does the SCOPE have good reliability (internal consistency)?
3. Does the SCOPE have good validity (convergent and discriminant validity)?
4. Does the SCOPE have good content validity i.e. does it capture the domains relevant to the concept of social inclusion?

5.3 Methods

Data for this study were collected as part of the OCTET Social Outcomes Study, described in the social networks study in *Chapter 2*. As with previous studies, I carried out all patient interviews, data cleaning, entry, and analysis. The patient sample, study design, data collection procedure and data management for Study 4 are the same as Study 1, unless indicated otherwise.

5.3.1 Instruments used in the study

Social inclusion: *The Social and Community Opportunities Profile (SCOPE – short version)* (Huxley et al., 2012) is a 48-item self-complete or clinician/researcher assisted questionnaire developed to assess social inclusion in mentally ill populations. The instrument contains two sub-scales, *Satisfaction with Opportunities* and *Perceived*

Opportunities. The Satisfaction with Opportunities contains 8 items scored on a 1-7 Likert scale (terrible, displeased, mostly dissatisfied, mixed, mostly satisfied, pleased, delighted), while the Perceived Opportunities contains 5 items scored on a 1-5 Likert scale (opportunities are extremely restricted, opportunities are quite limited, mixed, some good opportunities, plenty of opportunities). Scores for both sub-scales are summed and divided by the number of items. The instrument asks about patients' subjective perception of their own social inclusion and also has a range of objective indicators of participation and inclusion (e.g. employment, accommodation, social contact). The instrument was developed with the intention that objective indicators can be compared with survey data from the general population.

Capabilities: *The OxCAP-MH* (Simon et al., 2013). See Methods section of the Capabilities study, *Chapter 4* (p.137)

Health-related quality of life: *The EuroQol EQ-5D* (EuroQol-Group, 1990; Glick, 1999). See Methods section of the Social network study, *Chapter 2* (p.53).

Overall functioning: *The Global Assessment of Functioning (GAF)* (Hall, 1995). See Methods section of the Social network study, *Chapter 2* (p.54).

Psychopathology: *The Brief Psychiatric Rating Scale (BPRS)*. See Methods section of the Social network study, *Chapter 2* (p.53).

Objective social outcomes: *The Objective Social Outcomes Index (SIX)* (Priebe et al., 2008). See Methods section of the Social network study, *Chapter 2* (p.54).

All instruments are reproduced in full in *Appendix I*.

5.3.2 *Statistical analyses*

Data were checked for normal distribution using the one-sample Kolmogorov-Smirnov test of goodness of fit. Pearson correlations were used to test for association between instruments.

Feasibility

Feasibility has been defined as 'the ease and efficiency with which the questionnaire can be administered to the subjects' (Dickey et al., 1996, p.113). Feasibility in this study was evaluated in terms of simplicity, brevity and perceived patient acceptability. Specifically, the ease with which patients completed the questionnaire (e.g. need for clarification regarding question content), the time taken to complete it, and patients' unsolicited responses to the content of the questionnaire.

Reliability of the SCOPE sub-scales

Internal consistency – the statistical agreement between individual items in the scale indicating the extent to which the hypothetical construct is shared between the items – was assessed using Cronbach's alpha, the most widely used measure of internal consistency (Streiner and Norman, 2008). Interpretation of Cronbach's alpha was based on George and Mallery's (2003) widely used guidelines: >0.9 = Excellent, >0.8 = Good, >0.7 = Acceptable, >0.6 = Questionable, >0.5 = Poor, and <0.5 = Unacceptable. Inter-item correlations were also calculated as an alternative indicator of internal consistency, which has been advised for scales with a small number of items (Dilorio,

2005). Corrected item-total correlations (which determine the relationship of individual item to the overall scale score and therefore whether the item can be discarded) were calculated to assess redundancy of individual items, with scores between 2 and 8 considered acceptable (Streiner and Norman, 2008).

Construct validity of the SCOPE sub-scales

Floor and ceiling effects, which show the proportion of patients who achieve the highest and lowest possible scores, were considered present for individual items where more than 40% of patients scored either the lowest or highest scores (Streiner and Norman, 2008); for the SCOPE sub-scales total scores, floor or ceiling effects were considered present if more than 15% of respondents scored the lowest or highest possible score respectively (Terwee et al., 2007).

Convergent and discriminant validity of the SCOPE was assessed by correlating the total scores of the two sub-scales (Satisfaction with Opportunities and Perceived Opportunities) with existing measures of capabilities (OxCAP-MH), health-related quality of life (EQ-5D), illness severity (BPRS), overall functioning (GAF), and objective social outcomes (SIX).

It was anticipated that the Satisfaction with Opportunities and Perceived Opportunities sub-scales would correlate most strongly with the OxCAP-MH. The OxCAP-MH captures information about the patient's perceived freedom to achieve socially valued outcomes across multiple life domains, many of which are shared with the SCOPE (e.g. having suitable accommodation or meeting socially with friends).

Like the SCOPE, the OxCAP-MH is also a subjective, patient-report instrument, which should further enhance the observed association between the measures.

It was expected that the SCOPE sub-scales would have a more modest association with the EQ-5D Utilities and VAS and on the basis that health-related quality of life (captured in the domains of mobility, self-care, usual activities, pain/discomfort, and anxiety/depression) will have some (limited) relevance to the perception of one's opportunities as well as satisfaction with one's opportunities. As with the SCOPE, the EQ-5D is a subjective, patient-reported measure which is likely to increase the strength of association between the instruments.

In contrast, discriminant validity was expected to be evidenced by weaker associations with the BPRS, GAF and SIX. The BPRS and GAF capture information about symptom severity and functioning from the clinician/researcher's perspective, while the SIX represents objective 'facts' about the individual's social situation. As such, these instruments have less in common with SCOPE sub-scales in terms of the concepts they purport to measure and in terms of the perspective of the instrument scorer i.e. the clinician or researcher rather than the patient.

5.4 Results

Participant flow and follow-up is described in the Results section of Study 1, *Chapter 2* (p.60). Complete social inclusion data were available for 114 patients and all analyses were carried out on this sample. The socio-demographic and clinical characteristics of the sample are described in Study 1, *Chapter 2* (see **Table 1**, p.62). Interventions and

changes in legal status during 48-month follow-up are presented in **Table 2**, *Chapter 2* (p.65). Mean scores for the SCOPE's Satisfaction with Opportunities and Perceived Opportunities sub-scales are presented in **Table 16** together with two patient samples and a group of healthy controls collected by Huxley et al. (2012) in *Chapter 3* (p.116); objective indicators of social inclusion are presented together with data from national surveys in **Tables 17** and **18** (pp.118-119).

5.4.1 Feasibility

The questionnaire took 10 to 15 minutes to complete at interview (mean = 13.5, SD = 4.5). Of the 114 patients included in the study, three quarters (n = 84) completed all items of the SCOPE. All patients (n = 114) completed all items for the two sub-scales (13 items) plus the subjective social inclusion questions ('Overall, how do you feel about the extent to which you are included in society?').

5.4.2 Reliability of the SCOPE sub-scales

Internal consistency of the Satisfaction with Opportunities sub-scale as measured by Cronbach's alpha was 0.75, placing it in the "acceptable" range (Cohen, 1988; George and Mallery, 2003). Corrected item-total correlations for this analysis ranged from 0.31 to 0.64 indicating low redundancy of individual items (Streiner and Norman, 2008). Cronbach's alpha for the Perceived Opportunities sub-scale was 0.59 placing it in the "poor" range (George and Mallery, 2003). Corrected item-total correlations for this scale ranged from 0.20 to 0.47 and were therefore considered satisfactory (Streiner

and Norman, 2008). Mean inter-item correlations for the sub-scales were 0.26 for Satisfaction with Opportunities and 0.24 for Perceived Opportunities.

5.4.3 Construct validity of the SCOPE sub-scales

There was no evidence of floor or ceiling effects (>40% of respondents achieving either the highest or lowest scores) on individual items on the Satisfaction with Opportunities and Perceived Opportunities sub-scales (Streiner and Norman, 2008). Likewise, there were no floor or ceiling effects in the total scores for the respective sub-scales, with less than 15% of respondents scoring either the highest or lowest scores (Terwee et al., 2007).

Pearson correlations for the SCOPE sub-scale total scores and those of the OxCAP-MH, EQ-5D, BPRS, GAF and SIX are presented in **Table 23**. The SCOPE sub-scales correlated highly with one another (0.66, $p < .01$). There was a significant association between the OxCAP-MH and the Satisfaction with Opportunities (0.45, $p < .01$) and Perceived Opportunities (0.35, $p < .01$) sub-scales. Both sub-scales correlated significantly with the EQ-5D Utility scores (0.25, $p < .05$ and 0.23, $p < .01$) although only the Perceived Satisfaction sub-scale was significantly correlated with the EQ-5D VAS (0.25, $p < .01$).

Table 23 Pearson correlations for SCOPE sub-scales and measures of capabilities, quality of life, illness severity, functioning and social outcomes

	SCOPE *Satisfaction with Opportunities*	**SCOPE *Perceived Opportunities***	**OxCAP-MH**	**EQ-5D 3L**	**EQ-5D VAS**	**BPRS**	**GAF**
SCOPE *Perceived Opportunities*	0.66**						
OxCAP-MH	0.45**	0.35**					
EQ-5D-3L Utilities	0.25*	0.23**	0.46**				
EQ-5D VAS	0.17	0.25**	0.52**	0.47 **			
BPRS	-0.24*	-0.02	-0.49**	-0.46**	-0.48**		
GAF	0.21*	0.26	0.25**	0.36**	0.33**	-0.61**	
SIX	0.15	0.00	0.12	0.18	0.13	-0.18	0.67**

*SCOPE = Social and Community Opportunities Profile; EQ-5D = Euro-Qol Utilities; VAS = Visual Analogue Scale; BPRS = Brief Psychiatric Rating Scale; GAF = Global Assessment of Functioning; SIX = Objective Social Outcomes Index; ** Significant at the .01 level * Significant at the .05 level*

There was a statistically significant association between the Satisfaction with Opportunities sub-scale and the BPRS (-0.24, $p < .05$) and the GAF (0.21, $p < .05$) but not the Perceived Opportunities sub-scale. Note that higher scores on the BPRS indicate greater illness severity and a negative association with the SCOPE sub-scales would therefore be expected. There was no significant association between the SIX and either of the SCOPE sub-scales.

5.4.4 Sub-scale correlations with subjective perception of social inclusion

There was a significant positive association between the statement 'Overall, how do you feel about the extent to which you are included in society?' and Satisfaction with Opportunities (0.42, $p < .001$) and Perceived Opportunities (0.29, $p < .004$).

5.5 Discussion

The aim of Study 4 was to evaluate the SCOPE in a clinical research setting with psychosis patients in terms of its feasibility, psychometric properties and content validity.

5.5.1 Feasibility

The SCOPE had generally good feasibility. For all 48-items in the SCOPE, completion rates were high with 80 patients (70%) completing all items (Trauer, 2010). For the

two sub-scales, all patients completed all 13 questions. These completion rates were artificially high, however, because the sub-scales were used as principal outcomes in Study 2 and I therefore prioritised collection of these data when conducting the interviews. Completion times for the 48-items were between 10 and 15 minutes. When administered alone this might be considered relatively brief, but when embedded within a larger research interview (e.g. within an RCT) would be considered quite long. Indeed, within the context of the OCTET Social Outcomes Study interview, which took around an hour to complete, many patients had difficulty sustaining attention over the course of the interview and some items had to be omitted from the questionnaire in order to complete the interview. No patient acceptability issues were observed with regards to the content of the SCOPE (Huxley et al., 2012). The majority of patients (89%) were able to understand the questions without the need for additional explanation and many commented spontaneously on the relevance of the questions to their situation.

5.5.2 *Reliability of the SCOPE sub-scales*

For both sub-scales the internal consistency, as measured by Cronbach's alpha, was close to but slightly lower than the figures reported by Huxley et al. (2012). Huxley and colleagues report a Cronbach's alpha of 0.77 for Satisfaction with Opportunities and 0.62 for Perceived Opportunities, compared to 0.75 and 0.59 in this study. In most research settings, a Cronbach's alpha of 0.7 or greater is considered acceptable, while scores below this are considered "questionable" (Cohen, 1988; George and Mallery, 2003). In line with the accepted interpretation, the internal consistency of the Perceived Opportunities sub-scale found in this study would be considered "poor"

(George and Mallery, 2003). This suggests that measurement of the construct underlying the individual items of the scale, namely perceived opportunities, is unreliable.

The low reliability of this sub-scale is arguably attributable to the small number of items in the scale (n = 5), a fact that is recognised by the authors (Huxley et al., 2012). Nevertheless, it gives grounds for concern: Nunnally and Bernstein (1994) argue that a Cronbach's alpha of 0.7 is the minimum acceptable to establish reliability for a newly developed scale. In basic research, scales should yield scores of at least 0.8, while in contexts in which important (e.g. clinical) decisions are being made based on scores from a scale, reliability scores of greater than 0.9 should be expected (Streiner and Norman, 2008).

Since Cronbach's alpha is influenced by the number of items in the scale (generally increasing as the number of items increases), it has been argued that inter-item correlations are more relevant as an indicator of reliability for instruments with a small number of items (Dilorio, 2005), a point that is highlighted by Huxley and colleagues. Carmines and Zeller (1979) provide values of Cronbach's alpha for various combinations of different numbers of items and different average inter-item correlations (see Dilorio, 2005). Thus, a scale with four items and an inter-item correlation of 0.2 would be equivalent to a Cronbach's alpha of 0.5 while a scale with six items would have an alpha of 0.6 (figures for five items are not provided). Huxley and colleagues report a mean inter-item correlation of 0.251, while Study 4 yielded a slightly lower inter-item correlation at 0.235. An inter-item correlation of 0.235 with five items is likely to correspond to a Cronbach's alpha of between 0.5 and 0.6 – still

relatively small. On balance, then, the reliability of the Perceived Opportunities sub-scale does indeed appear to be poor.

The test-retest reliability of the SCOPE was not evaluated as part of Study 4 since this was established by Huxley and colleagues with a large student sample (n = 119) and found to be good (Huxley et al., 2012, p.48). The time and financial resources necessary to replicate this aspect of the instrument's reliability were considered prohibitive within the timeframe of this DPhil.

5.5.3 *Validity of the SCOPE sub-scales*

Of the instruments used to evaluate the convergent validity of the SCOPE sub-scales, the OxCAP-MH is on theoretical grounds the most closely associated, capturing information about the patient's capabilities (opportunities) to participate across a broad range of life domains. Additionally, the OxCAP-MH instrument – like the SCOPE sub-scales – is based on the patient's subjective appraisal of their own situation. Both sub-scales correlated significantly with the OxCAP-MH, as predicted, although this association was not very large. The association was slightly larger for Satisfaction with Opportunities (r = 0.45) than for Perceived Opportunities (r = 0.35).

As predicted, correlations between the EQ-5D and the SCOPE sub-scales were significant though more modest in size compared with the OxCAP-MH. Interestingly, the VAS correlated significantly with the Perceived Opportunities but not the Satisfaction with Opportunities sub-scale. This may have to do with to do with the phrasing of the VAS question which asks how the patient *perceives* their own health status rather than how satisfied they are with it (Brooks, 1996).

There was a small correlation between the BPRS and Satisfaction with Opportunities (-0.24) sub-scale but not with the Perceived Opportunities (-0.02), a pattern that was similar for the GAF (0.21 and 0.26). The BRPS captures information about symptom severity while the GAF assess the patient's overall functioning, both from the clinician/researcher perspective. There was no significant association between the SIX and either of the sub-scales, as expected, since the SIX captures objective 'facts' about the patients social situation – i.e. it is effectively unrelated to a patients' satisfaction with or perception of opportunities (at least at the population level, although association at the individual level might be higher).

Overall, there appears to be some evidence of convergence of the SCOPE sub-scales with instruments measuring theoretically related constructs – the OxCAP-MH and to a lesser extent the EQ-5D. There was also a significant positive association between patients' subjective perception of their own social inclusion ('Overall, how do you feel about the extent to which you are included in society?') and the SCOPE sub-scales. Likewise, there is evidence that the sub-scales show divergence from instruments that, on theoretical grounds, should not be associated (or only weakly associated), namely illness severity, overall functioning and objective social outcomes.

One obvious limitation of the validity analysis presented here is that although instruments such as the OxCAP-MH capture an individual's opportunities as well as actual participation in society, none of the comparison instruments were explicit measures of social inclusion, social participation or social capital (De Silva et al., 2005). Due to time limitations, additional measures of social inclusion and participation could not be included in my research interviews and data are consequently unavailable for such an analysis. In their original validation, Huxley et

al. (2012) included measures of social capital, participation and inclusion for comparison to establish the convergent validity of the SCOPE sub-scales, and also tested for association between the sub-scales and eight domains obtained from the SCOPE's objective social inclusion indicators (employment, health, education, housing, leisure, safety, finances, and family and friends), however, space limitations in this DPhil preclude replication of this analysis here.

As discussed in the introduction to this chapter, the patient samples used by Huxley et al. (2012) to assess the validity of the SCOPE were small (n = 43 for the Mental Health Service User group). The use of small samples for validity testing can be problematic since it might be argued that they are not representative of the population in question and therefore limit the generalisability of the findings. For the purposes of validity testing, larger samples are generally called for in the psychometric literature (e.g. Charter, 1999). The sample in Study 4 was more than twice as large as the Mental Health Service User group used by Huxley et al. (2012), which should increase the confidence in the results of the psychometric validation presented here.

A further concern about the patient groups used by Huxley and colleagues to validate the SCOPE is the lack of detailed information about their socio-demographic characteristics. Huxley et al. (2012) report the age and diagnosis of three patient groups – patients with common mental disorders (n = 40), a Mental Health Service User group (MHSU) (described as 'patients with severe mental illness') (n = 43) and a second MHSU group (for more details about the characteristics of these groups, see Methods of *Chapter 3* [p.105], or Huxley et al., 2012). Although age and gender are given for these patients, there is no further information about socio-demographic or clinical status, such as diagnosis, duration of illness, past hospitalisations,

interventions received, living situation, employment, and so on. The scant information about the patient groups on which the SCOPE was validated raises serious questions about whether the results can be generalised to other patient groups with severe mental illnesses and, if so, to which groups in particular. Further, concerns might be raised about the instrument's responsiveness including whether it can feasibly detect meaningful change or distinguish between different clinical populations.

5.5.4 *Content validity of the SCOPE*

Huxley and colleagues (2012) describe the SCOPE as having an overall modular structure in which the Satisfaction with Opportunities and Perceived Opportunities sub-scales form the core. At first glance, the SCOPE appears to have good content validity including a broad range of domains relevant to the concept of social inclusion (Baumgartner and Burns, 2014). On closer inspection, however, there appear to be some important missing dimensions. For example, the SCOPE has limited coverage of patients' access to goods or services, including but not limited to, access to consumer goods, access to legal advice, access to services provided by the local authority/city council. There is no coverage of stigma and discrimination. Stigma and discrimination are known to affect people with mental illness (Corrigan and Watson, 2002; Corrigan and Kleinlein, 2005; Hinshaw, 2007), and are a recognised barrier to social inclusion, yet are completely absent from the questionnaire. The SCOPE also has little coverage of political participation – another recognised core concept in social inclusion (Huxley et al., 2012; Levitas, 2006; Morgan et al., 2007). Although there is a question about voting in the last general election, it seems that for many patients a question about

voting in local elections or engagement in local politics (e.g. local authority or city Council initiatives, proposals for new building projects, designation of green spaces, etc.) might be more relevant.

Perhaps a more serious concern relates to the content validity of the SCOPE's sub-scales and the concepts they purport to measure. Specifically, it is not clear to what extent satisfaction with one's opportunities and perception of those opportunities lie at the core of social inclusion (see the introduction to *Chapter 4*). For example, a patient may have the perception that there are opportunities to engage in education – and be satisfied with the range of opportunities – but not actually take up those opportunities due, for example, to perceived stigma, family obligations, lack of motivation, and so on. As such, some patients might score highly on the sub-scales, having the perception that they have many opportunities and that they are satisfied with these opportunities, yet their actual participation might be relatively low. It is clear that perception of opportunities is not the same as actual participation. One way to address this issue might be to include additional questions that cover the same domains but that focus instead on what the patient believes they are capable of doing. These questions could then by subjected to reliability testing by comparing the patient's responses with those of an external observer, such as a relative, carer or health professional to assess the level of agreement.

5.5.5 Objective indicators of social inclusion

The SCOPE contains a range of objective indicators of social inclusion. Wherever social outcomes are used within healthcare, those using them face the problem of how

they ought to be interpreted. This is because the value of any given social situation or outcome depends on judgements about what is important (values), which can vary by social context, cultural background, individual priorities, and so on (Priebe, 2007). For example, it is unclear whether one kind of objective indicator (e.g. employment) is preferable to or more valuable than another (e.g. housing). This issue becomes especially problematic when multiple objective indicators are included in a single measure and combined into an index.

One solution to the problem is to use 'weighting' procedures (Trauer and Mackinnon, 2001). Weighting attempts to attach a value (weight) to individual indicators, increasing or decreasing the value (score) of the indicator relative to other indicators included in the measure so that they reflect these preferences. Huxley et al. (2012) steer away from weighting objective indicators on the basis of concerns that have been raised about the scales commonly used to rate the importance of different indicators (Evans, 1991; Schmidt, 1973; Stevens, 1957) and about the use of weighting procedures in general (Trauer and Mackinnon, 2001). Instead, they advocate the use of comparisons with population data obtained from national surveys. Objective indicators of social inclusion are reported **Table 17** and **18** in Study 2, *Chapter 3* (pp.118-119) where they are presented together with UK population data obtained from national surveys as well as data for two patient groups and a group of healthy controls collected by Huxley et al. (2012).

Huxley and colleagues (2012) highlight that an advantage of the objective indicators included in the SCOPE is that they are taken from UK national survey data and can therefore be used for comparisons with the general population. Such an approach has advantages (Kendall and Sheldrick, 2000) but depends on the availability and

accessibility of national survey data to which research samples can be compared. For the SCOPE, the majority of surveys from which objective social inclusion indicators were taken have either been discontinued, no longer contain the relevant item(s), or cannot be found.

Of the national surveys used for comparison with objective indicators of inclusion in the SCOPE – searched via the web (Google) and through the University of Oxford library service (SOLO) in May 2015 – The Health Survey for England (Health and Social Care Information Centre, 2015) is the only survey from the original list that is still being run in its original form. The *General Household Survey* has not been published since 2007; the *Home Office Citizenship Survey* (later the *Citizen Survey*) was discontinued in 2011 (UK Data Service, 2015); the *National Crime Survey* – now the *Crime Survey for England and Wales* – no longer contains the relevant item; *The Family and Children Survey* (referred to in the literature as the *Families and Children Study*) ended in 2008 (Administrative Data Liaison Service, 2015; National Centre for Social Research and Department for Work and Pensions, 2011); the *Citizenship Survey* ('People, Families and Communities') (2008) was discontinued in 2010 (UK Data Service, 2015). One of the objective indicators (Are you able to borrow a small sum of money if needed?) presented in **Table 17**, *Chapter 3*, is taken from the *Resource Generator* questionnaire (Webber and Huxley, 2007) and is not, in fact, part of any routine national survey. Consequently, there appear to be no normative data with which to compare this item.

The use of national survey data for normative comparisons, while attractive in principle, faces its own set of logistical challenges, notably data availability and access. Researchers and clinicians wishing to use the SCOPE should be aware of this

limitation. For those wishing to make comparisons with national survey data, one pragmatic solution would be to draw on novel or modified questions from contemporaneous national surveys, although such a strategy raises its own difficulties, such as ensuring that the instrument's overall validity is maintained.

5.5.6 Study limitations

This study was a pragmatic evaluation of the feasibility, psychometric properties and overall performance of the SCOPE using data from the OCTET Social Outcomes Study. Data were not collected specifically for the purposes of psychometric evaluation of the SCOPE and this analysis should be considered exploratory – an attempt to provide further testing and validation of the instrument with a different patient group. Further validation work, as described by Huxley et al. (2012) and others (Baumgartner and Burns, 2014; Coombs et al., 2013), should attempt to replicate and extend the findings reported here with larger samples. Specifically, testing with different diagnostic groups remains necessary as well as revaluation of the reliability and validity of the sub-scales. The instrument's sensitivity to change and responsiveness also remain to be established.

5.5.7 Summary and conclusions

The SCOPE is one of only a handful of measures designed to measure social inclusion among people with mental illness. Several literature reviews conclude that the instrument is generally robust although further testing and evaluation is necessary. In

this study I provide a critical evaluation of the SCOPE and its psychometric properties in a clinical sample with chronic psychotic illnesses. The instrument demonstrated good patient acceptability and was relatively easy to administer and score, however, it was slightly on the long side which may raise feasibility issues when it is administered with a battery of other measures such as in the context of a clinical trial. Of particular concern was the low internal consistency of the Perceived Opportunities sub-scale, raising questions about its reliability. The small and poorly specified patient groups used in the original validation of the instrument were also discussed as well as problems relating to the objective indicators of social inclusion and the provenance of normative data. Finally, I raised questions about whether the instrument covers all relevant aspects of social inclusion with some potentially core concepts being absent. These limitations notwithstanding, the SCOPE is arguably the best available instrument for measuring social inclusion in a mental health context at the present time. Further validation and testing with other patient groups should be the subject of future work.

Chapter 6: Psychometric validation of the OxCAP-MH

6.1 Introduction

6.1.1 Background

The *Oxford Capability Questionnaire Mental Health* (OxCAP-MH) was used as one of three main social outcomes measures in this DPhil. The OxCAP-MH is a novel multi-dimensional instrument developed for use as an outcome measure in mental health research (Simon et al., 2013). There is a need for standardised health and quality of life outcome measures with good psychometric properties and one aim of this DPhil was to carry out further evaluative work on the psychometric properties of the OxCAP-MH. The development of this instrument including a discussion of the theoretical background to the capability approach is described in detail in *Chapter 4*.

The OxCAP-MH was first piloted as part of the OCTET Trial (Burns et al., 2013) and initial testing indicated both the feasibility and validity of directly measuring capabilities in patients with severe mental illness (Simon et al., 2013; Vergunst et al., 2014). However, further work is required to establish the instrument's broader psychometric properties including the internal consistency, test-retest reliability,

convergent and discriminant validity, and sensitivity to change. This chapter describes the statistical evaluation of the psychometric properties of the OxCAP-MH.

6.1.2 Psychometric properties

Psychometrics is the field of study concerned with the measurement of psychological states, traits and abilities, including the development and validation of instruments to assess these properties. It was discussed in the Introduction to *Chapter 5* that the most important psychometric properties of an instrument are *reliability* and *validity*. Reliability is the ability of the instrument to measure the construct of interest consistently (e.g. at different time points) and is most commonly assessed in terms 'test-retest' reliability and internal consistency. Validity is the ability of the instrument to measure the construct that it purports to measure. The most important type of validity is construct validity (Schotte et al., 1997) which is made up of two subtypes: convergent validity and discriminant validity. Convergent validity describes the degree to which two measures of constructs that theoretically should be related are in fact related. In contrast, discriminant validity assesses whether concepts or measurements that should be unrelated are in fact unrelated (Campbell, 1959).

A further important psychometric property is sensitivity to change. An instrument's sensitivity is its ability to measure change – usually a change in health status – over time. Some authors have distinguished between sensitivity to change and responsiveness. S*ensitivity to change* refers to the ability of the instrument to measure any degree of change, while *responsiveness* reflects the ability to detect change over time that is clinically meaningful (Streiner and Norman, 2008). Sensitivity and

responsiveness are usually determined by evaluating the relationship between changes in clinical and patient-rated endpoints and changes in the instrument over time, usually within a clinical trial or observational study (Guyatt et al., 1987; Revicki et al., 2000). Although responsiveness – and how to interpret it – continues to be debated (Revicki et al., 2008) there are two broadly accepted methods for establishing change: distribution-based approaches and anchor-based approaches. In general, the recommended best practice in the evaluation of change is the calculation of both distribution-based estimates (e.g. effect size and standard error of measurement) and anchor-based criteria (e.g. patient or clinician ratings of change), including triangulation between methods (Revicki et al., 2006; Streiner and Norman, 2008).

Distribution-based approaches focus on the statistical features of the data produced by the instrument (Lydick and Epstein, 1993). One simple approach to assess change in the outcome of interest is to calculate a standard 'effect size' (Kazis et al., 1989). A more sophisticated method than the effect size is to calculate the standard error of measurement (SEM) (Fitzpatrick et al., 2004; 1999b; Wyrwich et al., 1999a). The SEM estimates the extent to which the observed change is true change rather than measurement error. Thus, any change score above the SEM can be considered statistically significant change in the sense that it is unlikely to have arisen by chance. One limitation of SEM is that it is based on information about scores at a single time point only rather than multiple time points. A more accurate measure of change would therefore require the calculation of the difference (S_{diff}) between the SEM at two time points in a longitudinal study (Fitzpatrick et al., 2004; Iverson, 2001).

Because statistically reliable change does not guarantee that change is clinically meaningful – it simply tells us that it is unlikely to have arisen from measurement

error – distributional approaches need to be complemented by anchor-based approaches (Norquist et al., 2004). *Anchor-based approaches* use scores from patient- or clinician-rated instruments as an external indicator ('anchor') of change. For example, patients can be asked whether their health is, compared to their previous assessment, (1) better, (2) the same, or (3) worse.

Where explicit patient ratings are unavailable, patients can be categorised into groups using data from a patient- or clinician-rated anchors of health status based on statistical criteria. Specifically, an interval defined as a half standard deviation (SD) around zero change (change between baseline and follow-up) represents the category 'no change' in health status; negative intervals beyond this interval represent the category 'worse' health status, and positive values beyond this interval represent the category 'better' health status (Norman et al., 2003). One advantage of this latter approach is that it does not depend on patients recalling their health status at baseline, which can be unreliable due to recall bias and memory lapse (Norman et al., 1997).

There is guidance in the literature on the interpretation of distribution-based estimates of change, including whether scores can be considered statistically meaningful (Cohen, 1988; Norman et al., 2003). Nevertheless, there is no widely accepted guidance on whether difference scores are meaningful from either a patient's or clinician's perspective.

Patient-rated vs. objectively rated capabilities

The OxCAP-MH was developed for use with patients with severe mental illness. Although there is evidence that capabilities can be accurately self-reported (Al-Janabi et al., 2013) it is necessary to distinguish between what people *think* they can do and what they can *actually* do. This is particularly relevant in a mental health context where cognitive, behavioural and affective responses might be significantly altered as a result of the illness. In the case of severe and particularly psychotic illnesses, it could be argued that patients' ratings of their own capabilities have low validity, in comparison to ratings made by external observers. To explore this, we conducted a pilot study in which patient-rated OxCAP-MH scores and scores obtained from an external observer known to the patient (e.g. care coordinator, support worker or carer) were tested for association.

The aim of this study was to establish the psychometric properties of the OxCAP-MH in terms of internal consistency, test-retest reliability, convergent and discriminant validity, and sensitivity to change in a clinical sample with psychotic illnesses.

6.2 Research questions

1. Does the OxCAP-MH have good reliability (internal consistency and test-retest)?
2. Does the OxCAP-MH have good validity (convergent and discriminant)?
3. Is the OxCAP-MH sensitive to change?

6.3 Methods

6.3.1 Sample

Data for this study were collected at baseline between 2008 and 2012 as part of the OCTET Trial (Burns et al., 2013). Patients were randomised at baseline and followed-up for one year. Inclusion criteria for the RCT are described in the Methods section of *Chapter 2*. Data for the test-retest reliability of the OxCAP-MH and the objective capability ratings were collected as part of the OCTET Social Outcomes Study in 2013, described in the Methods of *Chapter 2*.

6.3.2 Design and procedure

The reliability and validity analyses employed a cross-sectional design. The sensitivity to change analysis had a longitudinal design. Patient data were obtained through structured research interviews. Interviews for the OCTET Trial and OCTET Social Outcomes Study lasted approximately one hour (completion times for the OxCAP-MH were between five and ten minutes) and patients were reimbursed with £25 for each interview (Burns et al., 2013). Socio-demographic and clinical details were collected from medical records (see Methods, *Chapter 2*).

For the test-retest evaluation of the OxCAP-MH, all patients were contacted twice with the same postal questionnaire with a seven day interval between questionnaires. Questionnaires were accompanied by an addressed, pre-paid envelope. To eliminate bias due to changes in patients' mental state or social situation, patients were asked

the following question in the second questionnaire: *Since you last completed this questionnaire, has anything in relation to your mental health or social situation changed?* Patients who answered 'yes' to this question were excluded from the test-retest analysis.

Patient data for OxCAP-MH objective ratings analysis were taken from the 48-months follow-up interview while the corresponding objective ratings were obtained from the patient's care coordinator, support worker or carer at the time of the interview or via email/post within one week.

6.3.3 Instruments used in the study

The following instruments were used in the OxCAP-MH validation study:

Capabilities: *The OxCAP-MH* was developed for use as an outcome measure in mental health research (Simon et al., 2013). Initial testing of an 18-item version of the OxCAP-MH led to the removal of two items (home ownership and life expectancy) following factor analysis. In the first version, items 1 and 2 (*Does your health affect your daily activities compared to most people your age? / Are you able to meet socially with friends and relatives?*) were coded as dichotomous (yes/no) responses and then converted into a 1 to 5 scale (1=1 and 2=5) (Simon et al., 2013). In subsequent applications of the instrument, including the test-retest reliability, all 16 items were scored on 1 to 5 Likert scales (e.g. strongly agree, agree, neither agree nor disagree, disagree, strongly disagree) with higher scores indicating better capabilities. Scoring of the earlier version of the OxCAP-MH was based on a total summed score ranging from 16 to 80; in the final version of the instrument, items were summed and then

converted into a standardised 0-100 scale for each patient using the formula: 100 × (OxCAP-MH total score – minimum score)/range. The development of the OxCAP-MH instrument, including individual items and item reduction, is reported elsewhere (Simon et al., 2013; Vergunst et al., 2014).

Health-related quality of life: *The EuroQol EQ-5D* (EuroQol-Group, 1990; Glick, 1999). See Methods section of the Social network study, *Chapter 2* (p.53).

Overall functioning: *The Global Assessment of Functioning (GAF)* (Hall, 1995). See Methods section of the Social network study, *Chapter 2* (p.54).

Psychopathology: *The Brief Psychiatric Rating Scale (BPRS)*. See Methods section of the Social network study, *Chapter 2* (p.53)

Objective social outcomes: *The Objective Social Outcomes Index (SIX)* (Priebe et al., 2008). See Methods section of the Social network study, *Chapter 2* (p.54).

Instruments used in this study are reproduced in full in *Appendix I*.

6.3.4 Statistical analyses

Data were checked for normality using the one-sample Kolmogorov-Smirnov test of goodness of fit. Descriptive statistics of socio-demographic and clinical characteristics used means (SD) for normally distributed data, medians (IQR) for non-normally distributed data, and number (%) for categorical data. T-tests were used for normally distributed data, Mann-Whitney U tests for non-normal data, and Chi-square tests for categorical data.

Floor and ceiling effects

Floor and ceiling effects were calculated for all Likert scale items and considered present if more than 40% of patients scored the lowest or highest score respectively (Streiner and Norman, 2008); for total OxCAP-MH scores, floor or ceiling effects were considered present if more than 15% of respondents scored the lowest or highest possible score respectively (Terwee et al., 2007).

Reliability

The reliability of the OxCAP-MH was evaluated in the following ways. The internal consistency was assessed using Cronbach's alpha. Corrected item-total correlations were calculated to assess redundancy of individual items, with scores from 2-8 considered acceptable (Streiner and Norman, 2008). The test-retest reliability was established by calculating the intraclass correlation coefficient using a two-way random model with absolute agreement.

Validity

Construct validity of the OxCAP-MH was evaluated by comparing total OxCAP-MH score to existing health measures, namely the EQ-5D, GAF and BPRS. Convergent validity was assessed by calculating the Pearson correlation coefficients for the OxCAP-MH and the EQ-5D using UK tariff and VAS scores. Discriminant validity was determined by calculating the Pearson correlation coefficients for the OxCAP-MH, GAF, BPRS and SIX.

The EQ-5D was used to assess convergent validity because, of the instruments used in this study, it is believed on theoretical grounds, to be the most closely related to the OxCAP-MH. The EQ-5D captures health-related quality of life, which should show some correspondence with the broader concept of well-being captured by the OxCAP-MH, and it is also a subjective, patient-reported outcome measure (PROM), which should increase the statistical correspondence between the measures. In contrast, the GAF, BPRS and SIX would be expected to show a weaker association with the OxCAP-MH given that these are clinician-rated measures – the GAF and BPRS represent the clinician/researcher's impression of the patient's overall functioning and symptom severity respectively, while the SIX captures objective facts about their social situation.

Sensitivity to change

Baseline mean (SD), 12-month follow-up mean (SD) and internal consistency reliability coefficients were calculated for the OxCAP-MH (16-items). The baseline and follow-up SEM was calculated using the following formula:

$$SEM = \sigma_x \sqrt{1 - r_{xx}}$$

Where σ is the standard deviation of the score and r is the reliability of the instrument. SEM scores were calculated from the baseline and 12-month follow-up OxCAP-MH scores. SEMs were then used to obtain the S_{diff} using the following formula:

$$S_{diff} = \sqrt{(SEM_1^2 + SEM_2^2)}$$

There is currently no consensus about how many SEMs a score must change for it to be considered a clinically meaningful change for the individual. It has been argued that a difference of one-SEM frequently corresponds to a minimally important difference (Wyrwich et al., 1999b), although a more conservative approach can be used which multiplies the SEM by 1.96 and corresponds with the 95% confidence interval (Mitchell et al., 1993; Sloan et al., 1996). Using a higher SEM multiplier simply means that higher change scores are required to identify change scores that are unlikely to have arisen by chance.

For the anchor-based method, patients were classified into three groups based on the observed change in baseline and follow-up on the EQ-5D Utilities, EQ-5D VAS, BPRS and GAF. An interval defined as a half standard deviation around zero of the change score represented the category 'Same' health status, negative scores beyond this interval represented the category 'Worse' and positive values beyond this interval represented the category 'Better' (Norman et al., 2003).

Responsiveness of the OxCAP-MH was assessed by calculating effect sizes and standardised response means (SRM). Effect sizes were calculated using the following formula:

$$ES = \frac{M_2 - M_1}{SD_{baseline}}$$

Where M_1 is the mean score of baseline assessment, M_2 the mean score of the follow-up assessment, and $SD_{baseline}$ the pooled standard deviation (Cohen, 1988). The pooled standard deviation was calculated as follow:

$$SD_{pooled} = \sqrt{\frac{(SD_1^2 + SD_2^2)}{2}}$$

SRMs were calculated in the following way:

$$SRM = \frac{M_2 - M_1}{SD_{M2-M1}}$$

Where the numerator stays the same as for calculating ES, but the denominator represents the SD of the differences in mean scores. Interpretation of the magnitude of change for the ES and SRM was estimated using Cohen's (1988) criteria: <0.20 = trivial; ≥0.20 to <0.50 = small, ≥0.50 to <0.80 = medium; and ≥0.80 as large. Statistically significant changes in OxCAP-MH scores between baseline and follow-up were tested using paired t-tests.

Objective capability ratings

Objective OxCAP-MH ratings scores obtained from carers/health professionals were compared with patients' ratings using Pearson correlations.

All data were entered into SPSS version 20 (SPSS, 2011) and analysed using this programme.

6.4 Results

6.4.1 Sample characteristic

A total of 336 patients were randomised to the OCTET Trial. Of these, two patients withdrew and one was ineligible (Burns et al., 2013). Response rates to the individual items in the OxCAP-MH questionnaire ranged from 68% to 90% and were strongly

affected by the order in which the questions appeared within the broader OCTET Trial baseline interview rather than the questions themselves (Simon et al., 2013). Complete OxCAP-MH baseline data were available for 172 patients. Statistical analyses for the OxCAP-MH validation study were carried out on this sample. The characteristics of patients in this subsample did not differ significantly from the full cohort, other than there being more patients living homeless in the full cohort 35 (11%), compared to 3 (2%) in the sub-sample (**Table 24**).

Of the 172 patients included in the analysis, 124 (72%) were male, 101 (59%) were white, 43 (25%) were black, 16 (9%) were Asian and 12 (7%) were 'other', 153 (89%) had a primary diagnosis of schizophrenia, schizotypal or delusional disorder, while 19 (11%) had a diagnosis of other psychotic disorders (including bipolar disorder). Patients had a mean age of 38 years (SD = 11) and a mean illness duration of 13 years (SD = 10). At baseline, 147 (85%) of patients were receiving incapacity benefit; 142 (83%) had independent accommodation; 2 (2%) were in regular paid employment; 19 (11%) were married or lived with a partner. Socio-demographic and clinical characteristics of the sample are presented in **Table 24**.

Table 24 Socio-demographic and clinical characteristics of patients included in the OCTET Trial and OxCAP-MH validation study

	OCTET Trial missing data (n = 333)		OCTET Trial (n = 333) [1]		OxCAP-MH validation study (n = 172)	
	N	(%)	N Mean or Median	(%) (SD) or [IQR]	N Mean or Median	(%) (SD) or [IQR]
Age	0	(0%)	39.6	(11.4)	38.2	(11.2)
Sex	0	(0%)				
Male			224	(67.3%)	127	(72%)
Female			109	(33%)	48	(28%)
Years of education	4	(1.2%)	11.9	(1.9)	11.9	(1.9)
Ethnic origin	0	(0%)				
White British			204	(61%)	101	(59%)
Black			77	(27%)	43	(25%)
Asian			29	(9%)	16	(9%)
Mixed and other			23	(7%)	12	(7%)
Born in the UK	1	(<1%)	256	(77%)	137	(80%)
Marital status	2	(<1%)				
Single			247	(74%)	128	(74%)
Married/co-habiting			29	(9%)	19	(11%)
Separated/divorced			55	(17%)	25	(15%)

	OCTET Trial missing data (n = 333)		OCTET Trial (n = 333) [1]		OxCAP-MH validation study (n = 172)	
	N	**(%)**	**N Mean or Median**	**(%) (SD) or [IQR]**	**N Mean or Median**	**(%) (SD) or [IQR]**
Have children under 18 years	2	(<1%)	134	(40%)	67	(39%)
Living situation	2	(<1%)				
Independent accommodation			238	(72%)	142	(83%)
Supported accommodation			58	(17%)	27	(16%)
Homeless			35	(11%)*	3	(2%)*
Employment	1	(<1%)				
Incapacity benefit			292	(88%)	147	(85%)
Regular paid			2	(<1%)	2	(2%)
Voluntary/protected/sheltered			2	(<1%)	2	(2%)
Job seeker's allowance			14	(4%)	9	(5%)
Unemployed, no benefits			13	(4%)	7	(4%)
Other (student/pensioner)			9	(3%)	5	(3%)
Clinical diagnosis	0	(0%)				
Schizophrenia			283	(85%)	153	(89%)
Other psychoses			50	(15%)	19	(11%)
Brief Psychiatric Rating Scale	22	(7%)	38.7	(11.4)	37.3	(10.4)

	OCTET Trial missing data (n = 333)		OCTET Trial (n = 333) [1]		OxCAP-MH validation study (n = 172)	
	N	**(%)**	**N Mean or Median**	**(%) (SD) or [IQR]**	**N Mean or Median**	**(%) (SD) or [IQR]**
Global Assessment of Functioning	24	(7%)	38.7	(9.7)	40.5	(9.6)
Duration of illness (years)	8	(2%)	14.3	(10.3)	13.2	(10.1)
No. of past psychiatric hospital admissions	21	(6%)	5	[3-9]	5	[3-8]

** Significant at the .05 level; Note: Percentages may not sum to 100 due to rounding*

[1] *Sample included in OCTET Trial final analysis and used for published OxCAP-MH paper (Simon et al., 2013)*

6.4.2 Floor and ceiling effects

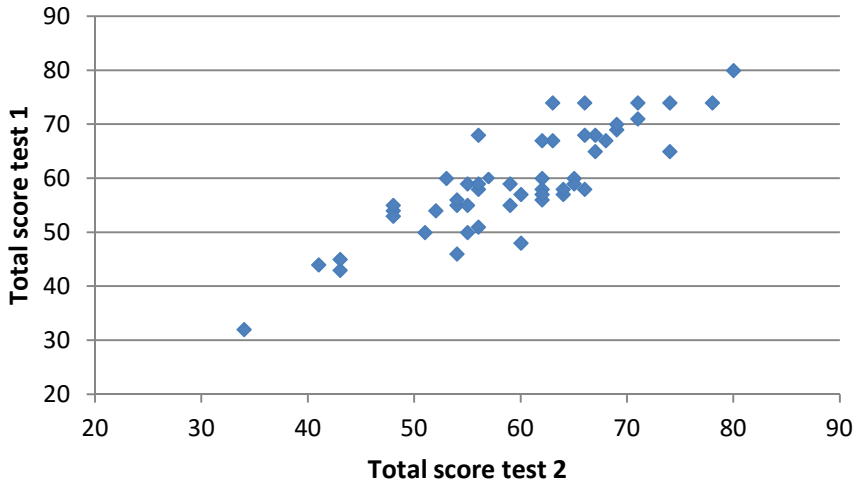
A ceiling effect was identified in two items with 42% of respondents reporting having 'very suitable' accommodation and 43% reporting feeling 'very safe' walking alone near their home; a floor effect was observed in one item with 43% of respondents reporting 'never' losing sleep over worry in the past four weeks (*Appendix II*). Overall, however, there was no evidence of floor or ceiling effects in the total OxCAP-MH scores, with less than 15% of respondents scoring either the highest or lowest scores (Terwee et al., 2007).

6.4.3 Reliability of the OxCAP-MH

The OxCAP-MH was found to have substantial internal consistency with Cronbach's alpha of 0.79. Corrected item-total correlations were considered satisfactory and ranged from 0.20 to 0.59 (Streiner and Norman, 2008). Of the 311 test-retest reliability questionnaires sent out, 57 were completed at both time points and returned. Patients who returned the questionnaire were more likely to have independent accommodation compared to the overall sample contacted (86% vs. 71%, $p<.05$), but otherwise did not significantly differ in their baseline socio-demographic characteristics. Patients who answered 'yes' to the questions 'Since you last completed this questionnaire, has anything in relation to your mental health or social situation changed?' were excluded from analysis (n = 5). Two questionnaires were excluded due to missing data. A sample of 50 was retained for analysis.

The test-retest reliability analysis generated a single-measure intraclass correlation coefficient of 0.86 ($p < .001$) (**Figure 6**). Linear regression produced a standardised coefficient of 0.86 ($P < .001$) and adjusted R^2 of 0.73, supporting the substantial reliability observed.

Figure 6 Test re-test reliability based on total scores collected one week apart (n = 50)



6.4.4 Validity of the OxCAP-MH

Pearson correlations between OxCAP-MH total scores and the other instruments are presented in **Table 25**. Correlations were highest with the EQ-5D VAS ($r = 0.522$, $p < .001$, $n = 171$) and EQ-5D Utilities (0.452, $p < .001$, $n = 170$) followed by the BPRS ($r = -0.413$, $p < .001$, $n = 172$). The negative association with the BPRS was expected as higher scores on this instrument indicate poorer functioning. A weaker association was

observed between OxCAP-MH total scores and the GAF (0.240, p < .001, n = 171) and SIX (r = 0.118, p = ns, n = 172). Correlations between the individual items of the OxCAP-MH and established measures of symptom severity, functioning, and outcome are available in *Appendix III*.

Table 25 Pearson correlations between the OxCAP-MH total scores and established measures of illness severity, functioning and social outcomes

	OxCAP-MH	EQ-5D Utilities	EQ-5D VAS	BPRS	GAF
EQ-5D Utilities	0.452**				
EQ-5D VAS	0.522**	0.517**			
BPRS	-0.413**	-0.411**	-0.325**		
GAF	0.240**	0.233**	0.203**	-0.443**	
SIX	0.118	0.129	0.100	-0.056	0.159*

*EQ-5D = Euro-Qol Utilities; EQ-5D VAS = Euro-Qol Visual Analogue Scale; BPRS = Brief Psychiatric Rating Scale; GAF = Global Assessment of Functioning; SIX = Objective Social Outcomes Index; * Significant at the .05 level ** Significant at the .001 level*

6.4.5 Sensitivity to change

Complete data for the OxCAP-MH were available for 104 patients at both baseline and 12-months follow-up. The SEM values for baseline and follow-up and values for S_{diff} using the two criteria (one-SEM and 1.96*SEM) are presented in **Table 26**. Between baseline and follow-up there was a small increase in mean capability scores from 68 to 71 for this sample.

Table 26 SEM values for the OxCAP-MH at baseline and 12-months follow-up

	Baseline (T1)		**Follow-up (T2)**		**SEM Values**					
	n = 104		**n = 104**		**1 * SEM**			**1.96 * SEM**		
	Mean (SD)	**Alpha[1]**	**Mean (SD)**	**Alpha[1]**	**T1**	**T2**	**Diff.[2]**	**T1**	**T2**	**Diff.[2]**
OxCAP-MH	67.67 (13.80)	0.78	70.81 (11.85)	0.70	6.47	6.49	9.16	12.68	12.72	17.96

SEM = Standard error of the mean; [1] *Cronbach's alpha coefficient;* [2] $S_{diff} = \sqrt{(SEM_1^2 + SEM_2^2)}$

Using the one-SEM of change criterion, a score of 6.47 on a 0 – 100 scale can be considered a statistically important difference. This cut off increases to 12.68 when the more conservative 1.96*SEM criterion is applied. The standard error of the difference (S_{diff}) shows that a minimally significant change from baseline to 12-months follow-up corresponds to a 9.16 points of change on a 0 – 100 scale; this threshold increases to 17.96 when the 1.96*SEM criterion is used.

Using the one-SEM S_{diff} criterion of statistically significant change between baseline and follow-up (9.16), 24 (23%) patients improved, 67 (64%) showed no change, and 13 (12%) deteriorated. For these three groups, the mean (SD) capabilities scores at 12-months follow-up were 74.5 (11.5), 70.0 (12.3) and 68.4 (8.8). Using the more stringent 1.96*SEM S_{diff} threshold of 17.96, 8 (8%) patients improved, 92 (88%) showed no change, and 4 (4%) deteriorated. These three groups had mean (SD) capabilities scores at 12-months follow-up of 74.8 (12.2), 70.7 (12.0) and 65.2 (5.6) respectively.

Complete data for the OxCAP-MH, EQ-5D, BPRS and GAF were available for 103 patients at both baseline and 12-months follow-up. Patient- and clinician-rated anchors split by health status category (Better, Same, Worse) are presented in **Table 27.** The table includes OxCAP-MH scores for the three categories at baseline and follow-up and the differences between the two (Change), responsiveness statistics (t-test), effect size and SRM. For all instruments there were a larger number of patients in the category 'Same' health status category compared to the 'Better' or 'Worse' categories.

For all anchors and all instruments the category 'Better' health status was associated with mean difference scores reflecting an improvement in capabilities scores. Conversely, for all anchors and all instruments except the GAF the category 'Worse'

health status was associated with mean changes reflecting deterioration in capabilities scores. This pattern was more consistent in the patient-rated anchors, namely the EQ-5D Utilities and VAS. The EQ-5D VAS showed the strongest evidence of responsiveness with improved scores in the 'Better' group, deteriorated scores in the 'Worse' group, and little change in the 'Same' group.

Examination of the effect sizes and SRMs indicates that responsiveness was larger for the patient-rated anchors (EQ-5D) than the clinician-rated anchors (BPRS and GAF), which were both statistically significant with small and medium effect sizes respectively, a pattern that was particularly evident in the 'Better' category. Effect sizes and SRM for the clinician-rated anchors were in the 'trivial' to 'small' range for both the 'Better' and 'Worse' categories indicating low responsiveness (Günther et al., 2008).

Table 27 OxCAP-MH mean (SD) change scores, effect size, and SRM for patient-rated anchors (n = 103)

	EQ-5D Utilities			EQ-5D VAS			BPRS[2]			GAF		
	Better	**Same**	**Worse**	**Better**	**Same**	**Worse**	**Better**	**Same**	**Worse**	**Better**	**Same**	**Worse**
OxCAP-MH	**n = 26**	**n = 51**	**n = 26**	**n = 35**	**n = 53**	**n = 15**	**n = 22**	**n = 46**	**n = 35**	**n = 34**	**n = 37**	**n = 31**
Baseline	58.96	57.39	63.42	56.11	60.64	62.07	59.50	59.80	58.54	59.50	60.57	57.55
	(6.50)	(9.54)	(8.46)	(9.25)	(7.45)	(10.92)	(7.57)	(10.29)	(7.73)	(9.79)	(7.57)	(9.39)
Follow-up	61.50	60.90	61.88	61.80	61.32	60.07	59.05	62.76	60.80	61.62	63.16	59.03
	(6.01)	(7.71)	(9.0)	(6.93)	(7.40)	(10.05)	(7.61)	(8.46)	(6.09)	(7.58)	(5.85)	(9.12)
Change	2.54	3.51	-1.54	5.69	0.68	-2.0	-0.45	2.96	2.26	1.76	2.59	1.48
	(5.33)	(6.70)	(6.46)	(6.39)	(5.63)	(6.55)	(5.93)	(6.36)	(7.10)	(7.90)	(5.78)	(6.22)
Pooled SD	6.26	8.67	8.73	8.17	7.43	10.49	7.59	9.42	6.96	8.70	6.76	9.26
t-statistic[1]	2.42*	3.74**	-1.21	5.26**	0.87	-1.18	-0.36	3.15*	1.88	1.30	2.73*	1.32
Effect size	0.41	0.40	-0.18	0.70	0.09	-0.19	-0.06	0.31	0.32	0.20	0.38	0.16
SRM	0.48	0.52	-0.24	0.89	0.12	-0.31	-0.07	0.45	0.32	0.22	0.45	0.24

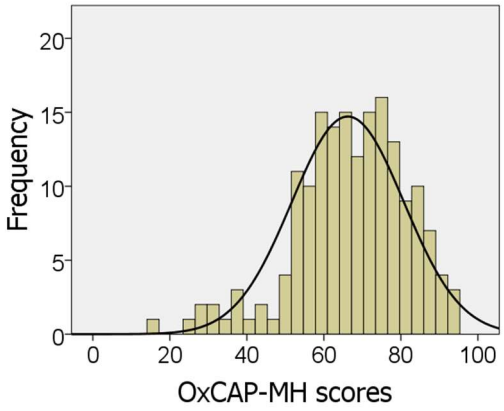
*Data are mean (SD) unless indicated; SRM = standardised response mean; * Significant at the .05 level; ** Significant at the .001 level*

[1] Paired t-test; [2]Higher BPRS score = greater symptom severity

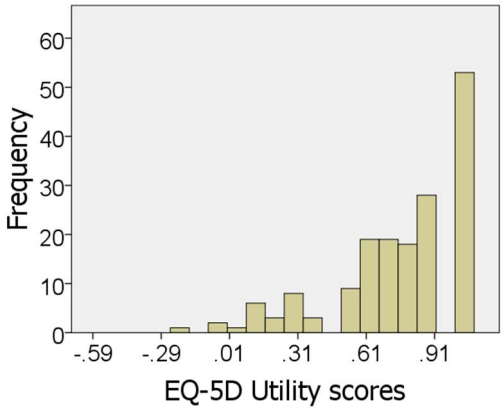
The distribution of total scores for the OxCAP-MH, EQ-5D Utilities, EQ-5D VAS, BPRS and GAF are presented in **Figure 7** (Frequency = number of cases). **Panel A** shows that total scores for the OxCAP-MH follow a normal distribution.

Figure 7 Distribution of patients' total scores for instruments used in psychometric validation (panels A – E)

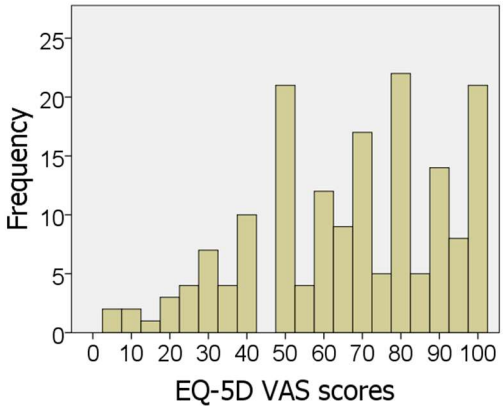
A. OxCAP-MH



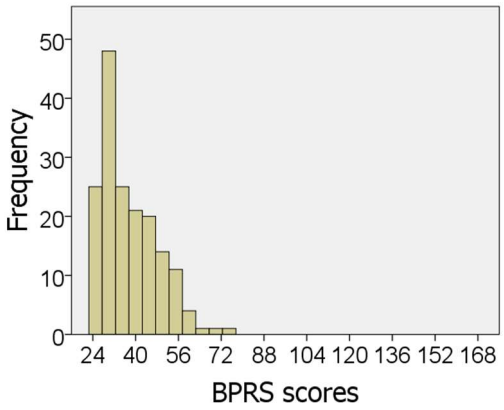
B. EQ-5D Utilities UK



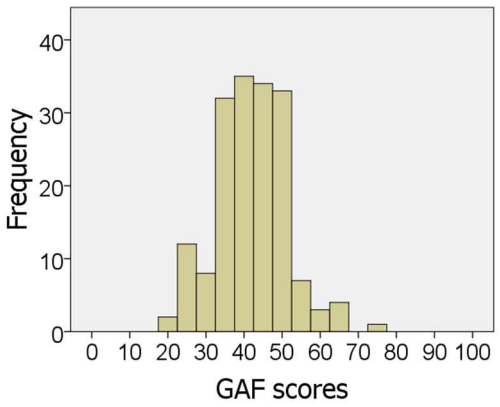
C. EQ-5D Visual Analogue Scale (scores collapsed to 5)



D. Brief Psychiatric Rating Scale



E. Global Assessment of Functioning (collapsed to units of 5)



Note: Frequency = number of cases

6.4.6 Objective capability ratings

Of the 65 carers/health professionals approached, 21 returned completed questionnaires, comprising 11 care coordinators, 9 support workers and 1 carer. Of these, 15 were obtained in person at the time of the patient interview (48-months follow-up) and 6 were returned via email within five days of the interview. One questionnaire was excluded because the patient's carer (mother) did not understand the purpose of the questionnaire. The objectively rated questionnaires (n = 20) were significantly correlated with patients' ratings ($r = 0.55$, $p < 0.05$).

6.5 Discussion

6.5.1 Main findings

This study reports the statistical evaluation of the psychometric properties of a multi-dimensional capability instrument designed for use in a mental health context. The instrument showed strong psychometric properties.

The OxCAP-MH was found to have good reliability: the internal consistency was evidenced by a Cronbach's alpha of 0.79 whilst the test-retest reliability measured by an intraclass correlation coefficient of 0.86 – both substantial correlations significant at the $p < 0.001$ level. Results also support the validity of the OxCAP-MH. The convergent validity of the instrument was demonstrated by its strong correlation with an established measure of health-related quality of life (EQ-5D). The modest correlation with overall functioning (GAF) and an objective measure of social

outcomes (SIX) supports the divergent validity of the instrument. The strength of these associations can be partially accounted for by the theoretical relationship between the instruments.

The EQ-5D is a widely used generic measure of health-related quality of life. It has undergone extensive reliability and validity testing with a range of health conditions (Dyer et al., 2010; Janssen et al., 2011; Johnson and Coons, 1998; Johnson and Pickard, 2000; Pickard et al., 2007; 2008) and has arguably the closest theoretical association with the OxCAP-MH. The EQ-5D and OxCAP-MH both capture patients' subjective appraisal of their own quality of life evidenced by the strong and statistically significant correlation between the instruments. A perfect correlation between the instruments would not be expected, however, since the OxCAP-MH is designed to capture a much wider range of outcomes than the EQ-5D including health and non-health domains. The OxCAP-MH should capture health-related quality of life and well-being but, as a multi-dimensional measure, it should also capture *more*. Interestingly, the OxCAP-MH correlated more strongly with the EQ-5D VAS scores than with the Utility scores. One possible explanation for this is that the Utility scores capture specific aspects of quality of life – namely those that are health-related – while the VAS reflects the patient's judgement about their overall health status, which is arguably more in line with the aims of the OxCAP-MH which attempts to capture the patient's overall well-being (Simon et al., 2013).

In contrast to the EQ-5D, correlations with the GAF – a well-established clinician-rated measure of overall (clinical and social) functioning – was 0.24, while the association with the SIX – an objective index of social outcomes – was just 0.12. Again, these associations can be explained by the more distal theoretical relationship

between the GAF and SIX and the OxCAP-MH. The GAF score represents a patient's overall functioning as perceived by the clinician/researcher, while the SIX merely captures objective 'facts' about their social situation (like having employment) – neither would be expected to correlate highly with a patient's subjective appraisal of what they feel free to be and do i.e. their capabilities. The validity of the OxCAP-MH is further supported by its significant negative association with the BPRS. This indicates that there is a strong negative relationship between patients' capabilities and psychopathological symptoms. Associations between all instruments used in this study and the 16 individual items of the OxCAP-MH are presented in *Appendix III*.

6.5.2 Sensitivity to change

The results show that on average there was little change in mean capabilities scores between baseline and 12-months follow-up, a finding that is consistent with results from the OCTET Trial and subsequent secondary analyses (Burns et al., 2013, Rugkåsa et al., 2014b). The results show that using the one-SEM_{diff} criterion, a change of around 9.2 on the OxCAP-MH 0 – 100 scale is unlikely to be due to measurement error and can be considered on distributional grounds to be a true change in score. When the more conservative 1.96 × SEM criterion is applied, this threshold for true change increases to 18.0 points of change. It is important to remember that these changes are not necessarily clinically meaningful but rather represent differences that, on statistical grounds, are unlikely to have arisen by chance.

The inclusion of approximate 95% confidence intervals (1.96 * SEM or 1.96 * S_{diff}) substantially increased the minimum significant – or 'real' – change score required for

the OxCAP-MH. Fitzpatrick et al. (2004) note that 'for group-based evaluative research there is a risk that calculating minimum change scores by distributional methods adjusted for 95% confidence intervals will result in too conservative an approach with respondents who experience important deterioration being missed and treated as unchanged' (p.1413). The use of one-SEM or one-S_{diff} would be in keeping with methods used in several studies assessing change across a range of health-related quality of life instruments in patients with asthma, cardiac problems, Parkinson's disease, amyotrophic lateral sclerosis, and chronic obstructive pulmonary disease (Fitzpatrick et al., 2004; Norquist et al., 2004; Wyrwich et al., 1999a; 199b; 2002). In these studies, one-SEM was considered the optimal statistical criterion consistent with anchor-based evidence (Norquist et al., 2004). Using the one-SEM S_{diff} criterion, an individual change score between baseline and 12-months follow-up that is greater than 9 points would be considered an improvement or deterioration in capabilities scores that did not arise due to chance or measurement error.

The question of whether to use one-SEM (or one-S_{diff}) or to use confidence intervals and therefore more stringent criteria for minimal change partly depends on whether decisions are made with respect to groups or individuals – for example, interpretation of clinical trials, or an individual patient in a clinical context (Norquist et al., 2004). In general, the group context is associated with greater confidence in any given estimate of health-related quality of life while a clinician making health-related quality of life decisions at the individual level may opt for the more conservative approach gained from the confidence interval adjusted scores to determine change (Fitzpatrick et al., 2004; Norquist et al., 2004).

Distributional-based methods used in this study represent statistically meaningful change but cannot be strictly considered estimates of clinically meaningful change (Revicki et al., 2008). Clinically meaningful change requires anchor-based estimates of change based, ideally, on patients' judgement of change.

Inspection of **Table 27** shows that the responsiveness of the OxCAP-MH as reflected in patient- and clinician-rated anchors of change was on average quite small. Across all categories of change in health status (Better or Worse), only the 'Better' category for EQ-5D VAS had an effect size in the 'medium' range (Cohen, 1988); all others were in the 'trivial' to 'small' range. However, data from the patient-rated questionnaires are arguably more relevant to the question of change than the clinician-rated instruments because, as with explicit anchor-based questions (e.g., 'Since your last assessment, has there been an improvement or deterioration in your health state?'), they reflect a patient's subjective appraisal of their own health status. In this case the VAS is arguably the most parsimonious measure of a patient's current health status, since it asks patients, on a scale of 1 to 100, '…how good or bad is your health status today?' Interestingly, the data for the VAS move in the right direction with improvement in the 'Better' category, deterioration in the 'Worse' category and little change in the 'Same' category, providing tentative evidence of the OxCAP-MH's sensitivity to change.

An explicit patient-rated anchor of change was not available for this study and this limits the conclusions that can be drawn about clinically meaningful changes in patients' capabilities. The use of a patient-rated anchor of change is the recognised best practice for establishing clinically meaningful change (Revicki et al., 2008). Patient-rated anchors should include five categories – deteriorated a lot, deteriorated

a little, unchanged, improved a little, and improved a lot – with the 'deteriorated a little' and 'improved a little' being selected to calculate the magnitude of change (Streiner and Norman, 2008; Revicki et al., 2008). Future evaluations of the OxCAP-MH should include explicit patient-rated anchor questions.

A final point on the matter of sensitivity to change is that among the existing capabilities measures developed for use in health contexts, the evidence of sensitivity to change is limited and somewhat mixed (Comans et al., 2013; Flynn et al., 2013; Parsons et al., 2014). Coast and colleagues (2014) note that generic capabilities measures cover a very broad informational space – i.e. the entirety of the individual's life and not just their health for example – which may make it more difficult to demonstrate their sensitivity to change. These challenges notwithstanding, demonstrating the sensitivity to change of the OxCAP-MH remains essential if the instrument is to be useful for distinguishing different interventions and should be tackled in future studies.

6.5.3 Distribution of OxCAP-MH scores

The distribution of patients' total scores for any instrument are relevant because non-normal distributions can lead to a loss of information through floor or ceiling effects thereby compromising validity. Ceiling effects are a well-documented limitation of the EQ-5D and have been shown in a range of patient groups and the general population (Brazier et al., 2004; Janssen et al., 2013; König et al., 2009). Problems of sub-optimal distribution of scores have also been observed for the GAF. Reliability studies show that GAF scores can have restricted distributions and can be unreliable

– for example, in one study 20% of raters accounted for more than 50% of the spread of scores while other studies have found that deviations can be 20 points or more (Aas, 2011; Loevdahl and Friis, 1996; Yamauchi et al., 2001). The distributions of total scores for the OxCAP-MH, EQ-5D, BPRS and GAF are shown in **Figure 7**. The OxCAP-MH scores are notable for their normal distribution indicating that few patients scored in the highest or lowest percentiles and data are unlikely to be 'lost' due to floor or ceiling effects.

6.5.4 Patient-rated vs. objectively-rated capabilities scores

OxCAP-MH scores based on patients' own ratings of their capabilities and scores from objective raters were significantly correlated. This suggests that despite many of these patients having a severe mental illness, they are able to rate their own capabilities, and these ratings show relatively strong agreement with ratings made by external observers. However, it is not entirely clear how one should interpret such an association. While some agreement in scores would be necessary and expected, a high correlation would be surprising since many of the questions in the OxCAP-MH concern patients' subjective appraisal of their own capabilities, so one would not expect perfect agreement, even if the patient is well known to the external rater, as in this study.

6.5.5 Strengths and Limitations

The majority of concepts used to assess quality of life have been introduced into healthcare not on the basis of a theoretical model but rather on the basis of

convenience or intuitive appeal (Priebe, 2007). A major strength of the capabilities approach is therefore its theoretical pedigree. Sen's work proposes a model of human welfare that is based on substantive freedoms to achieve the things that an individual has reason to value rather than on relying on resource and desire fulfilment typical of many traditional quality of life frameworks (Robeyns, 2005). Moreover, the OxCAP-MH focuses on factors that link directly to peoples' quality of life rather than relying on proxies (such as health-related quality of life) as is the case with the EQ-5D.

Measuring capabilities remains a challenge, however, and there is ongoing theoretical discussion about which capability domains are most important and how they ought to be measured (Coast et al., 2008b; Coast et al., 2015). The capability approach is not directly linked with traditional conceptual frameworks of health and quality of life, and there are comparatively few capability measures with which to compare new instruments. The development and validation of a novel capability measure represents an important conceptual and methodological development within the capabilities literature.

The data used in this study could not fully address the question of sensitivity of the OxCAP-MH. In particular, the absence of a patient-rated anchor question at 12-months follow-up means that the clinical meaningfulness of the instrument could not be tested. This is a limitation of the study and should be addressed in future work.

The number of completed objective ratings was relatively small (n = 21). This was because collection of these data was commenced six months after the follow-up study began, and because the carers and health professionals who were approached were either too busy or unwilling to complete the questionnaire at the time of the interview,

or failed to return the questionnaires by email or post. Additionally, some of the patients did not have a formal carer or care coordinator.

Patients in this sample represent the more severe end of the illness spectrum and further work is needed to establish the feasibility and validity of using the instrument with other patient groups. Finally, it is also worth noting that male participants were slightly over represented in this sample and equal representation should be considered in future studies.

6.5.6 Summary

The statistical validation described above shows that the OxCAP-MH has good psychometric properties in terms of reliability and validity. Questions about the instrument's sensitivity to change remain, however, and further work with larger samples, that include explicit anchor-based questions based on patients' judgement of change, is necessary. The results support the use of using self-reported capabilities to assess outcomes in patients with severe mental illness.

Chapter 7: Summary and implications

7.1 Introduction

The core aim of this DPhil was to test the association between community psychiatric compulsion (CTOs) and long-term social outcomes in a group of high-need patients with psychotic illnesses. The relationship between the duration of inpatient compulsion and long-term social outcomes was also tested. It is the first study of its kind to do so. The importance of including social outcomes when evaluating interventions for patients with psychotic illnesses has been increasingly recognised and called for (Kisely et al., 2014; Priebe, 2007); however, the field remains under development and there are relatively few well-validated instruments. A further aim of this DPhil was therefore to carry out validation and psychometric testing of two recently developed social outcome measures, namely the SCOPE and the OxCAP-MH. In this chapter I summarise the empirical findings, then, with a focus on CTO outcomes, I explore possible explanations for the observed results and discuss their clinical and policy implications. In the final section I discuss social outcome measurement, the importance of well-validated measures and, based on the measures

used in this study, make recommendations about the choice of social outcome measures in future studies.

7.2 Summary of empirical findings

Study 1 tested the association between the number of days that patients were subject to a CTO intervention and the size of their social network at 48-months follow-up, as measured by the Social Network Schedule (SNS) (Dunn et al., 1990). No significant association was found. Likewise, there was no association found between the duration of involuntary hospitalisation and social outcomes at follow-up. There were also no significant between-group differences in social network size when data were analysed based on original arm of randomisation. Consistent with previous studies that have used the SNS with this population, patients were found to have on average relatively small social networks (a mean of 10 contacts encountered in the past month), and also had a higher proportion of family members in their networks, when compared with the general population (Becker et al., 1998; Palumbo et al., 2013). Also consistent with a number of previous studies, social network size was significantly associated with overall functioning (Evert et al., 2003; Howard et al., 2000) and negatively associated with psychopathology (Cohen et al., 1996; Meeks et al., 2001). In other words, patients who were more unwell had fewer contacts in their networks.

Using the same methodology, Study 2 tested the association between the duration of CTO treatment and social inclusion at follow-up using a relatively new social inclusion measure, namely the SCOPE (Huxley et al., 2012). The instrument's two sub-scales (Satisfaction with Opportunities and Perceived Opportunities) were used as the main

(subjective) outcomes while the Objective Social Outcomes Index (SIX) was used to assess objective social outcomes. Again, the duration of CTO treatment was not significantly associated with either of the SCOPE sub-scale scores or with SIX scores at follow-up. This latter finding was consistent with results from a secondary analysis of the OCTET Trial which found no improvement in SIX scores at one-year follow-up for patients on CTOs (Rugkåsa et al., 2014b). With respect to involuntary hospitalisation, there were no significant associations with the SCOPE sub-scales at follow-up. There were also no significant between-group differences when data were analysed based on original arm of randomisation. When compared with Huxley and colleagues' (2012) data, patients in this study had sub-scale scores that were similar to those reported for a sample with severe mental illness but lower than those reported for a group of healthy controls. The SCOPE's objective indicators of social inclusion were consistently lower when compared with data from UK national population surveys (Huxley et al., 2012).

Study 3 tested the association between CTO duration and patient capabilities, using a novel multidimensional outcome measures, the OxCAP-MH (Simon et al., 2013; Vergunst et al., 2014). Again, no significant associations were found between CTO duration and patients' capabilities scores at follow-up. There were also no between-group differences in capabilities scores when data were analysed by arm of randomisation. As in the two previous studies, the association between the duration of involuntary hospitalisation and social outcomes was not significant. The study also found that for the whole sample mean capabilities and health-related quality of life (as measured by the EQ-5D) showed on average little change across the 48-months of the study, a finding that is consistent with results from the OCTET Trial secondary analysis showing little change in quality of life over the first year of the study (Rugkåsa

et al., 2014b; Kisely et al., 2013). This finding provides further evidence of the generally chronic illness course experienced by patients in the OCTET sample.

The aim of Study 4 was to provide further validation and testing of the psychometric properties of one of the few available social inclusion measures designed for use in a mental health context, namely the SCOPE short version (Huxley et al., 2012). The instrument showed good feasibility (it was relatively straightforward to administer with this population) although was quite long to administer. More problematic was low internal consistency of the Perceived Opportunities sub-scale, which raises questions about its reliability. There were also questions about whether the instrument covered all relevant aspects of social inclusion with some potentially important missing domains such as stigma and discrimination. Concerns were raised about the choice of objective social inclusion indicators, in particular the problem of obtaining national survey data for comparison purposes (many of the surveys from which the questions were drawn no longer exist). On balance, the SCOPE performed relatively well and, given that the field is still in its early development, it is probably one of the most feasible and well-validated social inclusion measures currently available.

In Study 5 statistical methods were used to establish the psychometric properties of the OxCAP-MH (Simon et al., 2013; Vergunst et al., 2014). The instrument was found to have good reliability (internal consistency and test retest) and validity (convergent and discriminant). The instrument's sensitivity to change was evaluated using distributional methods, although further testing using anchor-based approaches (to establish clinically meaningful change) is necessary and should be the subject of a

future study. Overall, the OxCAP-MH appears to be a promising multi-dimensional patient reported outcome measure for use in mental health research.

7.3 Understanding the association between CTOs and social outcomes

Using a range of objective and patient reported outcome measures, Studies 1 to 3 failed to detect an association between the duration of CTO treatment over the 48-months of the study and patients' social outcomes at follow-up. I discussed in previous chapters that the consistent lack of association found across studies using different measures (all had small beta coefficients or IRRs) and the small confidence intervals in all regression analyses suggests a genuine lack of association rather than a spurious result arising due to measurement error or a lack of statistical power (Higgins and Green, 2011). It is nevertheless worth exploring several alternative explanations for the failure to detect a significant association. These relate to the nature of the outcome measures used, the frequency with which patients with severe mental illnesses are subject to coercion (and consequently the potential for 'desensitisation'), and CTO mechanisms of action, which remain poorly understood (Churchill et al., 2007).

The nature of the measures used

One explanation for a failure to detect a significant association between CTO duration and social outcomes – were such an association actually present – relates to outcome measures used. Specifically, it relates to the use of objective social outcomes, such as the number of contacts in the patient's social network (Study 1) or whether the patient

can work, live independently and meet socially with friends (Study 2). I discussed in Chapter 1 that objective social outcomes can be understood as 'distal' outcomes when compared to the more 'proximal' clinical outcomes and, as such, they can be more difficult to change and that change can take time (Priebe, 2007). In the context of the studies reported here, it is perhaps unrealistic to expect that a social-legal intervention such as a CTO will alter the patient's social network size or whether or not they have employment or independent accommodation. This argument is further supported by the fact that we are now quite certain that CTOs do not improve clinical outcomes (Kisely and Hall, 2014; Maughan et al., 2014), which are likely to be the most important mechanism through which CTOs influence social outcomes. Additionally, the current study was relatively long (4 years) so one might assume that at least some effect on objective social outcomes would be observable within this period (assuming effects are in fact present), although this hypothesis was not supported by the data here.

If there are doubts about whether objective social outcomes can adequately capture the effects of CTOs, even in the long-term, are subjective measures more likely to capture the effects? It might be argued that because of their restrictiveness CTOs have a more substantial impact on patients' personal freedoms and therefore quality of life and consequently would be more amenable to detection using subjective patient-rated outcome measures (e.g. the SCOPE sub-scales or the OxCAP-MH). This remains a possibility although it was not supported by the results of the studies reported here. Recent secondary data analyses from OCTET show that patients on CTOs felt no more coerced than voluntary patients at one year follow-up (Rugkåsa et al., 2014b), so CTOs may not greatly alter patients' perceptions of coercion after all; however, the relationship between compulsion and patients' perceptions of compulsion is a complex one (Canvin et al., 2013) and further work is required.

While instrument choice may be one reason for not detecting an association in some of the analyses – particularly those using objective social outcome measures – it is unlikely to fully explain the failure to detect associations across all measures in all studies presented here.

The 'desensitisation' argument

A second possible explanation for the failure to detect an association between the CTO intervention and social outcomes might be termed the 'desensitisation' argument. According to this argument, patients with a history of exposure to multiple compulsory interventions (e.g. involuntary hospitalisation) may become accustomed to such treatment to the extent that the use of subsequent compulsory interventions lose their 'authority' to influence the patient's decisions about adherence with treatment. This repeated exposure may be accompanied by a gradual blurring of the boundaries between formal compulsion and informal coercion (pressures imposed by mental health professionals, family members, carers, housing providers, etc., to encourage adherence with treatment) (Molodynski et al., 2010; Sjöström, 2006). Studies from inpatient contexts show that as many as half of patients who are voluntarily admitted to hospital report experiences of feeling highly coerced in their interactions with mental health services while many involuntarily admitted patients report no such experiences (Hoge et al., 1997; Iverson et al., 2002; Katsakou et al., 2011; Kjellin et al., 2006; Monahan et al., 1995).

In the CTO context, patients with a history of coercive encounters with health services might adopt a somewhat apathetic attitude towards compulsory interventions such that the initiation of a CTO is viewed by the patient as 'just another coercive event'

with no more significance than the many that have come before. As such, the effect of a CTO on a patient's subjective appraisal of their own life – and consequently their motivation to modify lifestyle choices, medication compliance, etc. – may be less dramatic than anticipated by healthcare professionals. This hypothesis has received some support from the secondary analysis of data from the OCTET Trial in which perceived coercion scores for patients in the CTO arm were no higher than those in the Control arm (Rugkåsa et al., 2014b).

CTO mechanisms of action

In three studies this DPhil found no association between CTO use and patients' social outcomes. Yet, even if CTOs could be shown to alter clinical or social outcomes, the mechanisms by which these changes occur would remain poorly understood (Churchill et al., 2007; Swanson et al., 1997; Swartz et al., 1999). The majority of tests of CTO effectiveness have not specified causal pathways between the intervention and outcomes, despite the accepted scientific consensus that evaluations should include identification of a theory base for the intervention (Campbell et al., 2007). Even when mechanisms have been specified, they have been difficult to separate from one another and the majority of studies have not been able to provide support either for or against their effects on relevant outcomes (Maughan et al., 2014).

In one of the only conceptual papers on the subject, Swanson and colleagues (1997) describe a model of specific mechanisms and pathways by which CTO outcomes might occur. They speculate that CTOs may improve long-term outcomes both directly and indirectly in several ways, including through stimulating case management efforts, mobilising supportive resources, improving individual

compliance with treatment in the community, reducing patients' psychiatric symptoms and dangerous behaviour, improving patients' social functioning and, lastly, reducing the chance of illness relapse and rehospitalisation. Because the majority of tests of CTO effectiveness have failed to find effects, these mechanisms have been difficult to confirm or reject empirically.

Studies of psychiatrists' views show that they broadly agree about most of the mechanisms through which CTOs are likely to influence outcomes (Manning et al., 2011; Romans et al., 2004) and that these generally overlap with those proposed by Swanson and colleagues (1997). These studies, conducted in the UK and New Zealand respectively, asked psychiatrists to rate on five-point Likert scales the importance of nine potential mechanisms in terms of their influence on how CTOs work (**Table 28)** (Manning et al., 2011; Romans et al., 2004). Again, however, these putative mechanisms have not been empirically generated and only reflect psychiatrists' views about which mechanisms are most important; in practice, the evidence shows overwhelmingly that CTOs do not alter outcomes, so establishing the effects of specific mechanisms has been difficult.

Table 28 Psychiatrists' views about the importance of different mechanisms in influencing how CTOs work

Mechanism	**UK (n = 566)**	**NZ (n = 202)**
	Rank (mean)	**Rank (mean)**
1. Ensuring compliance with medication	1. (1.95)	1. (2.10)
2. Ensuring a period of greater stability in patients' lives	2. (2.26)	3. (2.24)
3. Signalling to patients they have a major mental illness	3. (2.28)	2. (2.15)
4. Commits service providers to the patient	4. (2.76)	4. (2.39)

5. Gives others the confidence to care for the patient	5. (2.79)	7. (2.83)
6. Binds community services into place	6. (2.89)	6. (2.45)
7. Encourages the patient to accept responsibility	7. (3.15)	5. (3.42)
8. Mobilises social support for the patient	8. (3.25)	8. (3.19)
9. The patient gives up conflict areas to external agents	9. (3.30)	9. (3.32)

NOTE: Scores range from 1 (very important) to 5 (not important at all)

By far the most frequently described mechanisms in the CTO literature are those that are 'service-based', that is, those that centre on the provision of additional human and material resources for the patient. A number of early studies of CTO effectiveness reported improvements in clinical and service use outcomes but only when the CTO intervention is accompanied by increased service contacts (Steadman et al., 2001; Swanson et al., 2013; Swartz et al., 1999). What is unclear from these studies is whether CTO benefits were attributable to the increased service contact alone, or whether there were other factors relevant to the CTO process that also improved outcomes, as Swartz et al. (1999) have argued. More recently, a large population-based follow-up study reported that CTOs reduce all-cause mortality at 24-months follow-up, a finding that was attributed to increased service contact, although the study was uncontrolled and the authors concede that the effects of uncontrolled confounders could not be ruled out (Kisely et al., 2013). Studies in which the number of service contacts during follow-up have been controlled for, such as in Burns and colleagues' (2013) recent RCT, have found no benefits for patients subject to CTOs.

These studies raise an important question: can CTO benefits be attributed to increased service contact alone – are they nothing more than a comprehensive care package with some (limited) legal authority – or is there something more to them?

More importantly, if CTOs do achieve better outcomes through increased service provision alone, then can their use be justified given that these outcomes might be achieved through less restrictive means?

If it is true that CTO effects can be attributed to better community care then the remaining 'legal authority' component may be a worthy target in future investigation of CTO effects and mechanisms. The legal power of CTOs is most likely to influence outcomes through certain psychological pathways – for example, the patient's attitudes towards mental health services or the therapeutic alliance (Van Dorn et al., 2006) – which might affect treatment compliance and engagement with services. The potential of psychological mechanisms to shape CTO outcomes could be measured using scales that assess patients' attitudes to treatment or perceived coercion. However, as already discussed, there is evidence that patients on CTOs feel no more coerced than voluntary patients (Rugkåsa et al., 2014b), so, for the majority of patients, being on a CTO may have little impact on cognitive or affective processes, or at least those processes that are likely to shape relevant outcomes.

In summary, I have explored several potential explanations for the failure to find an association between the duration of CTO treatment and social outcomes. CTOs are complex interventions and a large number of individual and service level factors are likely to interact in complex ways to influence outcomes (Swanson et al., 1997). The fact remains that the mechanisms through which CTOs operate are poorly understood and, in light of their continued and increasing use internationally, clarifying these pathways should be a priority. In the absence of this knowledge, we continue to use a highly restrictive intervention while ignorant of whether the putative clinical or social benefits might be achieved through less restrictive – and therefore more ethical –

interventions. Taken together, the results from studies presented here add to a growing body of evidence that CTOs do not improve clinical outcomes for patients (Kisely and Hall, 2014; Maughan et al., 2014; Rugkåsa et al., 2014a) and the most parsimonious explanation is that there is no meaningful or measurable association between CTOs and social outcomes. As ever, further work with larger samples is needed to confirm these findings

7.4 Involuntary hospitalisation and social outcomes

A subsidiary aim of this thesis was to test the relationship between involuntary hospitalisation and social outcomes, though no significant associations were found. I examined above several possible explanations for the absence of a relationship between CTOs and social outcomes, some of which may generalise to involuntary hospitalisation. However, for a number of reasons, the relationship between involuntary hospitalisation and social outcomes is likely to be more complex and therefore difficult to elucidate. First, involuntary hospitalisation is arguably more relevant as a means to contain immediate risk (Holloway et al., 2011) rather than to achieve clinical or social benefits for patients. Thus, where therapeutic gain does occur, it may in fact be quite limited (Kallert et al., 2011; Priebe et al., 2011). In the majority of cases, disentangling the importance of risk management versus therapeutic gain is likely to be challenging at best and in many cases impossible, yet, without a specified outcome, it will not be possible to specify the mechanisms (Campbell et al., 2007). Second, involuntary hospitalisation is not a discrete intervention or intended as such – it is a set of often unspecified interventions

including, for example, pharmacotherapies, physical containment, and practical and psychological support – which are likely to interact in complex ways to shape outcomes. As such, the mechanisms through which involuntary hospitalisation influences clinical and social outcomes are likely to be numerous and hard to disentangle. So far, there have been few attempts to clarify this complex relationship and much further work is needed.

7.5 CTOs: Implications for clinical practice and policy

The results from the three studies reported here show no benefit for CTOs in terms of improved social outcomes, even in the longer-term. This naturally raises questions about the continued use of CTOs in clinical practice, particularly in light of the growing body of evidence that they confer no clinical benefits in terms of reducing relapse and subsequent readmission to hospital (Kisely and Hall, 2014; Maughan et al., 2014; Rugkåsa et al., 2014a). Moreover, given their significant infringement on personal liberties, the absence of either clinical or social benefits for the patient make their continued use difficult to justify.

The message from the OCTET Trial (Burns et al., 2013) and two earlier RCTs (Swartz et al., 1999; Steadman et al., 2001) is clear: CTOs do not improve outcomes for patients. If health professionals take an evidence based approach to treatment, then it is hard to see how the continued use of CTOs can be justified. At the very least the evidence is a call for pause and reflection (see, for example, Szmukler, 2015). Two years after the publication of the OCTET Trial, CTOs continue to be used in the UK and around the world, although there are some signs that the evidence is being reflected upon.

In a recent government consultation on changes to the Mental Health Act (1983) code of practice, the Royal College of Psychiatrists noted the evidence of the OCTET Trial and other RCT evidence, conceding that 'recent research findings indicate that CTOs have no significant effects on hospitalisation and other service use outcomes' (p.16), but do not go as far as calling for greater restrictions on their use (Royal College of Psychiatrists MHA Consultation, 2014). The College notes that while CTOs are still available to clinicians, clinicians should be encouraged to 'think harder' about the appropriateness of the intervention and should justify their decisions.

In a 2013 House of Commons post legislative review of amendments to the 2007 Mental Health Act (House of Commons, 2013) , the Committee acknowledges the results of the OCTET Trial and the limited evidence base for CTO effectiveness, noting that there is no 'support in terms of any reduction in overall hospital admission to justify the significant curtailment of patients' personal liberty' (p.26). In light of these findings the Committee recommends that Ministers review the current operation of CTOs. These recommendations were largely ignored in the government's final report on changes to the Mental Health Act (1983) code of practice (UK Government MHA code of practice consultation, 2015). The report makes no reference to OCTET or other empirical evidence and states that the Code should not discourage clinicians from using CTOs (p.55):

> *We have not taken on board any comments which would require changing the Act or which suggested that the Code should explicitly discourage the use of CTOs. Our view remains that the decision whether to place a particular patient on a CTO is a matter for clinical judgement in the light of the other available options.*

Outside of the policy debates, what alternative to the CTO intervention are available to clinicians? Guidance for the treatment and management of patients with severe mental illness and high need remains largely unchanged, namely that high quality long-term support in the community should be the priority. Sustained improvements in outcomes are more likely to be achieved through engaging the patient's social networks and mobilising social and community support for the patients, rather than through brief interventions in institutional environments (Thornicroft et al., 2004). Many patients are also likely to benefit from earlier intervention and from individually tailored interventions which they find more acceptable and are therefore more likely to adhere to (Johnson, 2011).

7.6 Remarks on social outcome measures

I discussed in the introductory chapter that social outcomes occupy an important place in the evaluation of interventions for patients with psychotic illnesses (Gilbody et al., 2002; Priebe, 2007). Yet, when compared with the assessment of clinical outcomes, methods to assess social outcomes are much less developed. The majority of social outcome measures have not been introduced into research or clinical practice on the basis of psychological models, have been subject to limited psychometric testing, focus on a limited number of domains, are used inconsistently and, consequently, often fail to to deliver (Burns and Patrick, 2006; Priebe, 2007). An important further aim of this DPhil was therefore to contribute to the development and validation of two recently developed social outcome measures, the SCOPE and OxCAP-MH.

The SCOPE and OxCAP-MH are different instruments, both in terms of the concepts they assess and their overall structure. The SCOPE is more structurally complex: it contains both patient-rated elements and objective indicators of social inclusion, is longer (containing three times as many items as the OxCAP-MH) and covers a greater range of domains. While the broad coverage of domains is a strength – most of the domains that are generally accepted as important to the concept of social inclusion are included (Huxley et al., 2007; Morgan et al., 2007) – it is also a potential weakness. Specifically, the breadth means that that concept is more difficult to define and therefore harder to operationalise. The development and application of a social inclusion measure that covers all relevant aspects and is still usable within routine clinical or research settings is an ambitious undertaking and it is likely that any attempt will in some ways fall short. I have discussed the limitations of the SCOPE elsewhere, including gaps in its conceptual content, reliability of the sub-scales, and its length, yet it remains one of the few social inclusion measures available for use in a mental health context. If social inclusion is a relevant concept for evaluating outcomes for people with severe mental illness, as it appears to be, then further work on the conceptualisation and measurement is clearly needed (Morgan et al., 2007).

The OxCAP-MH is a very different social outcome measure. It is a generic, patient-rated outcome measure that emphasises individual freedom to be and do the things that matter personally and socially to the individual. The OxCAP-MH is, in the broadest sense, a measure of human flourishing or well-being. It has several advantages. First, unlike many other social outcome measures, it has a distinguished theoretical pedigree that stems from Sen's (1979, 1993, 1999b) concept of capabilities, which has already demonstrated its utility in many other academic and applied disciplines. Second, as a framework for understanding well-being, the capabilities

approach does not rely on resource and desire fulfilment typical of many traditional quality of life frameworks (Robeyns, 2005), but focuses on substantive freedoms to achieve functionings that are valued by the patient. Third, the OxCAP-MH is easy to administer and score and it has robust psychometric properties (Simon et al., 2013; Vergunst et al., 2014).

In summary, deciding on social outcomes measures to evaluate interventions is challenging and no ideal measure exists for all purposes (Priebe, 2007; Thornicroft and Slade, 2014). Instrument choice will depend on the aims of the study, the specific research question and the availability of validated instruments, among other things (Trauer, 2010). Whatever instruments are chosen to capture social outcomes, a combination of objective and subjective indicators are likely to be necessary. For subjective indicators, there is an emerging consensus that patient-rated measures should be given greater prominence with some arguing that they should be the primary approach in the evaluation of mental health intervention (Thornicroft and Slade, 2014). Space limitations mean that it is not possible to make general recommendations about the use of social outcome measures. However, among the instruments used in this DPhil, the OxCAP-MH is arguably the most innovative and promising, particularly in light of the growing emphasis placed on the use of patient reported outcome measures in the evaluation of mental health interventions (Thornicroft and Slade, 2014).

7.7 Closing remarks

This DPhil thesis used a range of objective and subjective patient reported measures to investigate the association between the duration of CTO treatment and social outcomes at 48-months follow-up. No significant relationships were found: CTOs were associated with neither improvement nor deterioration in social outcomes. Likewise there was no significant association between the duration of involuntary hospitalisation and patients' social outcomes. Together with the growing body of evidence showing that CTOs do not improve clinical outcomes, this DPhil adds further weight to the case that CTOs represent an unacceptable and unjustifiable infringement of patients' liberties. In their current form, CTOs function more as a means of social control than therapeutic gain or improving patients' social situation. Their continued use should be carefully reconsidered.

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Appendices

Appendix I: Patient interview booklet (48-months follow-up)

Oxford Health NHS
NHS Foundation Trust



Oxford Community Treatment Order Evaluation Trial



SOCIAL OUTCOME INSTRUMENTS

Randomisation Date
(DD•MM•YY)
☐☐•☐☐•☐☐

Assessment Date
(DD•MM•YY)
☐☐•☐☐•☐☐

Participant ID
☐☐☐

Interviewer
☐☐

CONTENTS

	Section	Page
1	Instructions to researchers…….	3
2	Administrative Data……..	4
3	Socio-Demographic: Self And Home……...	5
4	Social Networks Schedule (SNS)…….	7
5	Social and Community Opportunities Profile (SCOPE)……...	15
6	Health-related Quality of Life (EQ-5D)……..	23
7	Patient Capabilities Questionnaire (OxCAP-MH)……	25
8	ICEpop CAPability measure for Adults (ICECAP-A).....	28
9	Admission Experience Survey (AES)……...	29
10	Continuity of Care Questionnaire…….	30
11	Brief Psychiatric Rating Scale (BPRS-24)……...	32
12	Global Assessment of Functioning (GAF)……...	34
13	EQ-5D (self-completion sheet)…….	35

SECTION 1: INSTRUCTIONS TO RESEARCHER

- Questions in **bold** are compulsory. All patients must be asked these questions

- Note scoring codes in the footer:

  888 = not applicable (questions in **bold** cannot be scored 888)
  777 = missing (data unavailable and cannot be found)
  666 = refused to answer (patient does not wish to answer this question)
  555 = 'don't know' (patient does not know the answer to this question)

SECTION 2: ADMINISTRATIVE DATA

VARIABLE NAME	VARIABLE	CODE	DATA ENTRY
ID	***Participant ID number***		☐☐☐
assessdate_t5	***Date of assessment for social outcomes interview***	dd•mm•yy	☐☐•☐☐•☐☐
consentdate_t5	***Date of consent to social outcome interview***	dd•mm•yy	☐☐•☐☐•☐☐
interviewer_t5	***Interviewer***	18 = FV 20 = Other (enter initials in booklet)	☐☐

clinserv _t5	***Clinical Service***	Name of Service:	_____ ☐☐
nhstrust_t5	***NHS Trust*** (Codes in appendix)	Name of Trust:	_____ ☐☐
sample_t5	***Sample***	1= AOT & forensic 2=CMHT 3=Learning disability 4=Crisis team 5=Rehabilitation team 6=EIS 7=Other 8=Not applicable	☐
samplespec_t5	If 'other', specify		_____
admission_t4_to_t5	***Has there been an admission since T4?***	0 = No 1 = Yes	☐
admissiondates_t4_to_t5_self	*Record admission dates, T4 to T5* *(self-report)*		…… ……
legalstatus_t4-t5_self	*Record changes in legal status, T4 to T5* *(self-report)*		…… ……
inpatient_at_t5	***Is the patient an inpatient at T5?***	0 = No 1 = Yes	☐

SECTION 3: SOCIO-DEMOGRAPHIC CHARACTERISTICS

employc_t5	**Current employment status**	1=unemployed, no benefits 2=job seekers allowance 3=sickness benefit 5=voluntary/protected/sheltered 4=other (e.g. student/pensioner) 6= regular paid, full-time 7=regular paid, part-time	☐
employsepcv_t5	If 'other', specify	……	

marriage_t5	**Marital status**	1=single 2=married/co-habiting 3=separated/divorced 4=girlfriend/boyfriend	☐
children0_t5	**Do you have any children?**	1=Yes 2=No	☐
children1_t5	If 'yes', are any of your children under 18 years old?	1=Yes 2=No	☐
children2_t5	If 'yes', where do the children live?	1=living with participant 2=living with separated partner 3=other	☐
children2sp	If 'other', specify	……	
children3_t5	If not living with children, contact frequency?	1=regular contact (monthly +) 2=infrequent 3=no contact	☐

livingwhere_t5	**Current accommodation** (self-reported)	1=independent (including living with friends, family) 2=supported 3=homeless	☐
livingwith_t5	If 'independent', who else does participant currently live with?	1=alone 2=with partner/family 3=other (i.e. friends and flat mates)	☐

pcq1height_t5	**What is your current height?** (please record cm)	(use Google conversion system)	☐☐☐
pcq2weight_t5	**What is your current weight?** (please record kilograms)		☐☐☐

pcq3religion	**Which religion, religious denomination or religious body, do you belong to?**	1 = Christian 2 = Jewish 3 = Muslim 4 = Other 5 = None	☐
fathersoccup	**What is (or was) your father's occupation?**	…… (Code retrospectively using Appendix II)	
socialclass	The National Statistics Socio-economic Classification Analytic Classes ***(see appendix II for examples)*** 1 = Higher managerial and professional occupations 1.1 Large employers and higher managerial occupations 1.2 Higher professional occupations 2 = Lower managerial and professional occupations 3 = Intermediate occupations 4 = Small employers and own account workers 5 = Lower supervisory and technical occupations 6 = Semi-routine occupations 7 = Routine occupations 8 = Never worked and long-term unemployed		☐

Objective Social Outcomes Index (SIX)

Ask 'friendship' question (4). Complete other boxes retrospectively using responses from previous section and Capabilities questionnaire

sixemploym	*Employment*	*0=none* *1=voluntary/protected/sheltered* *2=regular employment (including part-time)*	☐
sixhouse	*Accommodation*	*0=homeless* *1=sheltered or supported accommodation* *2=independent accommodation*	☐
sixpartner	*Partnership/family*	*0=living alone* *1=living with partner or family*	☐
sixfriend	***Friendship***	***0=not meeting a friend in the last week*** ***1=meeting at least one friend in the last week***	☐
sixscore	*Total Score*		☐

SECTION 4: SOCIAL NETWORKS SCHEDULE (SNS)

Dunn, M., O'Driscol, C., Dayson, D., Wills, W., Leff, J. (1990). The TAPS project 4: an observational study of the social life of long-stay patients. British Journal of Psychiatry, 157, 842-848.

Instructions

1. **Use accompanying score sheet**
2. **Explain this section to patients in the following way:**

➔ *This section asks about your social contacts and relationships*

➔ *First, I will ask you to recall the names of anyone you have met or socialised with over the past month*

➔ *Next, we will go through the list of names one at a time and I would like you to tell more about the sort of relationship you have with these people, for example, whether they are friends, acquaintances or hospital staff, how often you see them, whether or not you can confide in them, and so on.*

Note: if the patient does not wish to give the contact's actual name they can use a different name (or make one up, though this may get confusing); the name is only used as a reference for the patient so they know who they are talking about.

3. **Listing names: ask the service user the following (record on page 12)**

➔ *Where were you yesterday and what did you do?*
➔ *Who did you have contact with in each setting*?

Continue to elicit all contacts by asking further questions:

➔ *Is there anyone that you have seen in the past **week** who hasn't been mentioned yet?*
➔ *Is there anyone that you have seen in the last **month** who hasn't been mentioned yet?*
➔ *Is there **anyone else** that you have been in touch with by telephone or letter who hasn't been mentioned yet?*
➔ *Is there anyone that we have missed out whom you feel is important to mention?*
➔ *Did you **travel** anywhere? Any **Birthdays? Parties? Movies? Meals?** Anyone else at **work/placement?***

4. **<u>Scoring</u>**

Once names are have been recorded, go through the names one at a time and rate the quality of social contact using the score sheet

5. **<u>Conclusion</u>**

After scoring all names, ask patient whether they have thought of any other friends during the scoring process. If yes, record as above.

Summary of SNS codes (Quality of Social Contacts)

sns_gen	**Gender:** Is the contact male or female
	1 = Male 2 = Female 777 Missing

sns_loca	**Location:** Is the contact mostly seen at home, in a healthcare setting, or outside a healthcare setting? ***Q. Where do you mostly meet with/see _____?***
	1 = Home 2 = Healthcare setting (hospitals, day centres, or other healthcare setting) 3 = Non healthcare setting (e.g. café, pub, park or other public space, work place) 777 = Missing

sns_desig	**Designation:** What is the designation of the contact? ***Q. Is _____ a friend / fellow service user / family?***
	1 = Hospital staff 2 = Hospital patient 3 = Community staff *(this includes carers who are financed in the community as part of an adult care scheme, as well as volunteers who make contact with the service user because of his or her illness)* 4 = Community patient 5 = Relative *(this includes people related by marriage or through "common law marriage")* 6 = Social acquaintance *(includes companions who may or may not be friends and are not members of another category)* *7* = Neighbour *(this designation takes precedence over social acquaintance)* 8 = Workmate 9 = Service contact *(this consists of those contacts who provide a service to the service user, independent of the service user being a psychiatric patient. These are services used by most people e.g. shopkeepers, GPs, priests)* 10 = Other *(this category should only be used if the contact cannot be allotted to any of the afore-mentioned groups)* 11 = Nobody named 777 = Missing

sns_freq	**Frequency of Contact** ***Q. How often do you see _____?***
	4 = Daily (4 times per week +) 3 = Weekly (up to 3 times per week) 2 = Monthly to fortnightly 1 = Less than monthly but seen during the last month 0 = Not in contact during last month/ telephone contact only 777 = Missing

****** CUT OFF POINT ******

If the contact is at least monthly (even if by telephone/letter), please ask the following further questions.

It may become apparent during the following questions that some of the people listed are delusional figures or are deceased. If this is the case, delete their names from the coding sheet.

sns_miss	**Would miss or not:** Is the named person someone the service user would miss if they had no further contact with them? ***Q. If you no longer were able to see _____ would you miss them?***
	1 = Would be missed (yes) 2 = Would not be missed (no) 777 = Missing value

sns_intensity	**Intensity of interaction:** *for each pairing of service user and contact, the highest level of interaction that occurs between them is the one that is rated. Any appropriate prompt questions can be used. Start with "**active**" question, then move down to "**intermediate**" and finally "**passive**" to determine rating.*
	3 = Active ***Q. Do you have conversations with _____? (Yes)*** (this involves a continued verbal interchange. Other features can be the presence of the service user's motivation to be involved and a degree of reciprocity)
	2 = Intermediate ***Q. Do you and _____ do practical things together such as household tasks or do things for each other, for example, borrow cigarettes? (Yes, but no for 3)*** (this involves the exchange of articles or the performance of a practical task together with someone else or performing a service for someone such as running an errand. This occurs in the absence of any significant verbal interchange and must involve some degree of reciprocity and motivation as opposed to passive compliance.)
	1 = Passive ***Q. When you meet do you just greet each other briefly and say no more? If you are with _____ in the same room do you just sit quietly together without speaking? (Yes, but no to 2 & 3)*** (this represents a minimal level of interaction, typically the service user sits alongside someone else without talking. If the service user meets someone, their interchange is limited to a greeting and reply only. You can rate practical tasks here, provided they are ones that the service user is expected to comply with as part of their role as a service user, for example washing dishes at the request of a staff member)
	777 = Missing

sns_upset	**Upsetting Contacts:** *does contact with the individual upset (burdens or harasses) the service user?* ***Q. Does _____ upset you when you are with them?***	
	1	Not upsetting
	2	Upsetting
	777	Missing

sns_friend	**<u>Friendship</u>:** *ask whether the service user regards the contact person as a friend or not.* ***Q. Is _____ a friend, relative or just an acquaintance?***	
	1	Relative
	2	Not a friend (acquaintance= not a friend)
	3	Friend
	777	Missing

sns_conf	**<u>Confidant</u>:** *the service user is asked whether the listed person is someone they confide in. If the service user is only confiding the content of their delusions this is also categorised as confiding, providing they are confiding to a selected few.* *If the service user describes the contact as confiding and yet has already described them in terms of a passive or intermediate interaction, please go back to the section on level of interaction and reconsider with the service user the amount of conversation that takes place.* ***Q. Do you confide in _____?*** ***Q. If you have a personal worry, do you share your feelings with _____ about it?*** ***Q. Is _____ someone you talk to about your personal worries/feelings?***	
	1	Not confidant
	2	Confidant
	777	Missing

Social Network Schedule (SNS) : score sheet

Contact name or initials	**Lives w/ patient** 0 = No 1 = yes	**Gender** 1 = male 2 = female	**Location** 1 = home 2 = health sett. 3 = non-health	**Designation** 1 to 11	**Frequency *** 0 1 2 3 or 4	**Miss** 1 = yes 2 = no	**Intensity** 1 = active 2 = intermed. 3 = passive	**Upsetting** 1 = no 2 = yes	**Friend** 1 = relative 2 = acquaint 3 = friend	**Confidant** 1 = no 2 = yes
1		sns_gend_1	sns_loca_1	sns_desig_1	sns_freq_1	sns_miss_1	sns_intensity_1	sns_upset_1	sns_friend_1	sns_conf_1
2		sns_gend_2	sns_loca_2	sns_desig_2	sns_freq_2	sns_miss_2	sns_intensity_2	sns_upset_2	sns_friend_2	sns_conf_2
3		sns_gend_3	sns_loca_3	sns_desig_3	sns_freq_3	sns_miss_3	sns_intensity_3	sns_upset_3	sns_friend_3	sns_conf_3
4		sns_gend_4	sns_loca_4	sns_desig_4	sns_freq_4	sns_miss_4	sns_intensity_4	sns_upset_4	sns_friend_4	sns_conf_4
5		sns_gend_5	sns_loca_5	sns_desig_5	sns_freq_5	sns_miss_5	sns_intensity_5	sns_upset_5	sns_friend_5	sns_conf_5
6		sns_gend_6	sns_loca_6	sns_desig_6	sns_freq_6	sns_miss_6	sns_intensity_6	sns_upset_6	sns_friend_6	sns_conf_6
7		sns_gend_7	sns_loca_7	sns_desig_7	sns_freq_7	sns_miss_7	sns_intensity_7	sns_upset_7	sns_friend_7	sns_conf_7
8		sns_gend_8	sns_loca_8	sns_desig_8	sns_freq_8	sns_miss_8	sns_intensity_8	sns_upset_8	sns_friend_8	sns_conf_8

* If the contact is <u>at least monthly</u> (even if by phone/letter/email), ask subsequent questions, otherwise score 888

Contact name or initials	**Lives w/ patient** 0 = No 1 = yes	**Gender** 1 = male 2 = female	**Location** 1 = home 2 = health sett. 3 = non-health	**Designation** 1 to 11	**Frequency *** 0 1 2 3 or 4	**Miss** 1 = yes 2 = no	**Intensity** 1 = active 2 = intermed. 3 = passive	**Upsetting** 1 = no 2 = yes	**Friend** 1 = relative 2 = acquaint 3 = friend	**Confidant** 1 = no 2 = yes
9		sns_gend_9	sns_loca_9	sns_desig_9	sns_freq_9	sns_miss_9	sns_intensity_9	sns_upset_9	sns_friend_9	sns_conf_9
10		sns_gend_10	sns_loca_10	sns_desig_10	sns_freq_10	sns_miss_10	sns_intensity_10	sns_upset_10	sns_friend_10	sns_conf_10
11		sns_gend_11	sns_loca_11	sns_desig_11	sns_freq_11	sns_miss_11	sns_intensity_11	sns_upset_11	sns_friend_11	sns_conf_11
12		sns_gend_12	sns_loca_12	sns_desig_12	sns_freq_12	sns_miss_12	sns_intensity_12	sns_upset_12	sns_friend_12	sns_conf_12
13		sns_gend_13	sns_loca_13	sns_desig_13	sns_freq_13	sns_miss_13	sns_intensity_13	sns_upset_13	sns_friend_13	sns_conf_13
14		sns_gend_14	sns_loca_14	sns_desig_14	sns_freq_14	sns_miss_14	sns_intensity_14	sns_upset_14	sns_friend_14	sns_conf_14
15		sns_gend_15	sns_loca_15	sns_desig_15	sns_freq_15	sns_miss_15	sns_intensity_15	sns_upset_15	sns_friend_15	sns_conf_15
16		sns_gend_16	sns_loca_16	sns_desig_16	sns_freq_16	sns_miss_16	sns_intensity_16	sns_upset_16	sns_friend_16	sns_conf_16

* If the contact is <u>at least monthly</u> (even if by phone/letter/email), ask subsequent questions, otherwise score 888

Contact name or initials	**Lives w/ patient** 0 = No 1 = yes	**Gender** 1 = male 2 = female	**Location** 1 = home 2 = health sett. 3 = non-health	**Designation** 1 to 11	**Frequency *** 0 1 2 3 or 4	**Miss** 1 = yes 2 = no	**Intensity** 1 = active 2 = intermed. 3 = passive	**Upsetting** 1 = no 2 = yes	**Friend** 1 = relative 2 = acquaint 3 = friend	**Confidant** 1 = no 2 = yes
17		sns_gend_17	sns_loca_17	sns_desig_17	sns_freq_17	sns_miss_17	sns_intensity_17	sns_upset_17	sns_friend_17	sns_conf_17
18		sns_gend_18	sns_loca_18	sns_desig_18	sns_freq_18	sns_miss_18	sns_intensity_18	sns_upset_18	sns_friend_18	sns_conf_18
19		sns_gend_19	sns_loca_19	sns_desig_19	sns_freq_19	sns_miss_19	sns_intensity_19	sns_upset_19	sns_friend_19	sns_conf_19
20		sns_gend_20	sns_loca_20	sns_desig_20	sns_freq_20	sns_miss_20	sns_intensity_20	sns_upset_20	sns_friend_20	sns_conf_20
21		sns_gend_21	sns_loca_21	sns_desig_21	sns_freq_21	sns_miss_21	sns_intensity_21	sns_upset_21	sns_friend_21	sns_conf_21
22		sns_gend_22	sns_loca_22	sns_desig_22	sns_freq_22	sns_miss_22	sns_intensity_22	sns_upset_22	sns_friend_22	sns_conf_22
23		sns_gend_23	sns_loca_23	sns_desig_23	sns_freq_23	sns_miss_23	sns_intensity_23	sns_upset_23	sns_friend_23	sns_conf_23
24		sns_gend_24	sns_loca_24	sns_desig_24	sns_freq_24	sns_miss_24	sns_intensity_24	sns_upset_24	sns_friend_24	sns_conf_24

* If the contact is <u>at least monthly</u> (even if by phone/letter/email), ask subsequent questions, otherwise score 888

SECTION 5: SOCIAL AND COMMUNITY OPPORTUNITIES QUESTIONNAIRE

Huxley, P., Evans, S., Madge, S., Webber, M., Burchardt, T., McDaid, D., & Knapp, M. (2012). Development of a social inclusion index to capture subjective and objective life domains (Phase II): Psychometric development study. Health Technology Assessment, Vol. 16, no, 1.

- *This section asks about your social opportunities and how you feel about the opportunities available to you*
- *It might sound like you have been asked some of these questions before, but all questions are slightly different, so please try and answer as accurately as possible*

Your Leisure Time…

scope1	**Are there any leisure, sports or entertainment facilities in your area?**	2 = yes 1 = no 555 = don't know (move to **Q3**)	☐
scope2	Do you currently use any leisure, sports or entertainment facilities in your area?	2 = yes 1 = no 888 = not applicable	☐
scope3	**How do you <u>feel</u> about the opportunities that you have to participate in leisure activities?** *[Show response card 3]*	1 = terrible 2 = displeased 3 = mostly dissatisfied 4 = mixed 5 = mostly satisfied 6 = pleased 7 = delighted	☐
scope4	Q4 excluded (obtain from socio-demographics section, if required)		
scope5	**What do you <u>think</u> about the general availability of community groups, clubs and organisations in your area?** *[Show response card 4]*	5 = There are plenty of opportunities 4 = There are some good opportunities 3 = Mixed 2 = Opportunities are quite limited 1 = Opportunities are extremely restricted	☐
scope6	**In the last 12 months, have you given UNPAID help to someone who is NOT a relative?** Examples of unpaid help include: shopping, running errands, child care, house / pet sitting?	*<u>0</u> = yes* 1 = no	☐
scope7	**Did you vote in the May 2010 general election?**	2 = yes 1 = no	☐
scope8	**How do you <u>feel</u> about the range of opportunities to be involved with community groups, clubs or organizations that are available in your area?** *[Show response card 3]*	1 = terrible 2 = displeased 3 = mostly dissatisfied 4 = mixed 5 = mostly satisfied 6 = pleased 7 = delighted	☐

Your Housing and Accommodation…

	NOTE: For the purpose of this survey a **household** is either: One person living alone **OR** a group of people (not necessarily related) living at the same address as their only or main residence with common housekeeping – that is, they normally share at least one meal per day or share the living accommodation (a living or sitting room).	
scope9	**What type of accommodation does your household occupy?**	3= **A whole house or bungalow** that is: • Detached • Semi-detached • Terraced (including end-terrace) 2=**A flat, maisonette, apartment** that is: • In a purpose-built block of flats or tenement • Part of converted or shared house (including bed-sits) • In a commercial building (for example, in an office building, or hotel, or over a shop) 1=**Mobile or temporary structure**: • A caravan or other mobile or temporary structure 0=**Homeless** ☐
scope10	**What do you <u>think</u> about <u>your</u> opportunities to access suitable accommodation?** *[Show response card 4]*	5 = There are plenty of opportunities 4 = There are some good opportunities 3 = Mixed 2 = Opportunities are quite limited 1 = Opportunities are extremely restricted ☐
scope11	**How do you <u>feel</u> about the range of opportunities for suitable accommodation that are available?** *[Show response card 3]*	1 = terrible 2 = displeased 3 = mostly dissatisfied 4 = mixed 5 = mostly satisfied 6 = pleased 7 = delighted ☐
scope12	**Do you have a car? How many cars or vans are owned, or available for use, by one or more members of your household?** (Include any company car or van if available for private use.)	0 = None 1 = One 2 = Two 3 = Three or more (please state) ☐
scope12a	If three or more cars, please state	Number of cars / vans ☐
scope13	**Roughly how many years have you lived in your area?** (name area if known)	Years lived in area: ☐☐

Your Work…

scope14	**What do you <u>think</u> about the opportunity to acquire suitable work in this local area?** *[Show response card 4]*	5 = There are plenty of opportunities 4 = There are some good opportunities 3 = Mixed 2 = Opportunities are quite limited 1 = Opportunities are extremely restricted ☐
scope15	**Which of these is currently most applicable to you?**	1 = Self employed 2 = In paid employment (f/t or p/t) 3 = Unemployed* 4 = Retired from paid work altogether* 5 = On maternity leave* 6 = Looking after family or home* 7 = Full time student/ at school* 8 = Long term sick or disabled* 9 = On a government training scheme* 0 = Something else (Please give details) *** Skip to Q18** ☐
scope15a	If something else, give details	…….
	For those in work…	
scope16	How do you feel about your opportunities to find suitable work? *[Show response card 3]*	1 = terrible 2 = displeased 3 = mostly dissatisfied 4 = mixed 5 = mostly satisfied 6 = pleased 7 = delighted ☐
scope17	Thinking about the seven days ending on Sunday how many hours did you actually work in your main job/business?	→ Write the number of hours in the box, and then go to **Q19** ☐☐
	For those not working…	
scope18	How do you <u>feel</u> about your opportunities to find suitable work? *[Show response card 3]*	1 = terrible 2 = displeased 3 = mostly dissatisfied 4 = mixed 5 = mostly satisfied 6 = pleased 7 = delighted ☐

Your Finances…

scope19	**Can you tell me what your main source of income is?**	1 = No source of income 2 = Earned income e.g. from employment, investment, property rental 3 = State Pension or Pension from a former employment 4 = State Benefits 5 = Other Source of Income (please state) 666 = Prefer not to say ☐
scope19a	If Other Source of Income (5), please state	…….

scope20 — **What is your personal annual income (before tax if applicable)?** ☐

ANNUALLY	MONTHLY	WEEKLY	
No Income At All	No Income At All	No Income At All	= 0
Less Than £7500	Less Than £625	£144.20	= 1
Between £7500 and £13500	Between £625 and £1125	Between £144.20 and £260	= 2
Between £13500 and £20500	Between £1125 and £1708	Between £260 and £394.20	= 3
Between £20500 and £27500	Between £1708 and £2292	Between £394.20 and £529	= 4
More Than £27500	More Than £2292	More Than £529	= 5
Prefer not to say	Prefer not to say	Prefer not to say	= 666
Don't know	Don't know	Don't know	= 555

scope21	**What do you <u>think</u> about your opportunities to increase your personal income?** *[Show response card 4]*	5 = There are plenty of opportunities 4 = There are some good opportunities 3 = Mixed 2 = Opportunities are quite limited 1 = Opportunities are extremely restricted ☐
scope22	**If you needed someone to lend you a small amount of money (e.g. for a local taxi fare), do you know anybody who would be able to do so within one week?**	2 = yes 1 = no (move to **Q24**) ☐
scope23	If yes, who is this person most likely to be?	6 = Immediate Family 5 = Wider Family 4 = Friend 3 = Neighbour 2 = Colleague 1 = Acquaintance ☐

scope24	**Overall, how do you <u>feel</u> about the range of opportunities to secure additional income that are available?** *[Show response card 3]*	1 = terrible 2 = displeased 3 = mostly dissatisfied 4 = mixed 5 = mostly satisfied 6 = pleased 7 = delighted ☐

Your Safety…

scope25	**Generally, how safe or unsafe do you feel living in your area?**	4 = Very safe 3 = Fairly safe 2 = A bit unsafe 1 = Very unsafe ☐
scope26	**During the past year have you been a victim of a crime or assault?**	*<u>0</u> = yes* 1 = no ☐
scope27	**How do you <u>feel</u> about your opportunities to live safely in your area?** *[Show response card 3]*	1 = terrible 2 = displeased 3 = mostly dissatisfied 4 = mixed 5 = mostly satisfied 6 = pleased 7 = delighted ☐

Your education…

scope28	**What is the highest qualification you have obtained?**	1 = No Qualifications 2 = CSE/ GCSE/ 'O' Level 3 = School Certificate or Matric/ City and Guilds Ordinary Level 4 = 'A' Levels/ City and Guilds Advanced Level 5 = Degrees/ Diplomas/ HNC/ HND 6 = Teaching qualification (excluding PGCE) 7 = Nursing or other medical qualification 0 = Other (please Specify) ☐
scope28a	Specify Other	……

scope29	**In the past 12 months were or are you enrolled on any full-time or part-time education course studying for any qualification even if you did not obtain them?**	2 = yes 1 = no ☐
scope30	**What do <u>you</u> think about the general availability of the educational opportunities in your area?** *[Show response card 4]*	5 = There are plenty of opportunities 4 = There are some good opportunities 3 = Mixed 2 = Opportunities are quite limited 1 = Opportunities are extremely restricted ☐
scope31	**How do <u>you</u> feel about the range of educational opportunities that are available to you?** *[Show response card 3]*	1 = terrible 2 = displeased 3 = mostly dissatisfied 4 = mixed 5 = mostly satisfied 6 = pleased 7 = delighted ☐

Your Health…

scope32	**In the last 12 months, how many times have you talked to, or visited a GP or family doctor about your own <u>physical health</u>? (Please do not include any visits to a hospital)**	4 = No Visits 3 = One or Two 2 = Three or More 555 = Don't know ☐
scope33	**In the last 12 months, how many times have you talked to, or visited a GP or family doctor about your own <u>mental health</u>? (Please do not include any visits to a hospital)**	4 = No Visits 3 = One or Two 2 = Three or More 555 = Don't know ☐
scope34	**In the last 12 months, how many times have you attended a hospital or clinic (as a day patient or an in-patient) for a <u>physical health</u> problem?**	4 = No Visits 3 = One or Two 2 = Three or More 555 = Don't know ☐
scope35	**In the last 12 months, how many times have you attended a hospital or clinic (as a day patient or an in-patient) for a <u>mental health</u> problem?**	4 = No Visits 3 = One or Two 2 = Three or More 555 = Don't know ☐

scope36	**How do you <u>feel</u> about your opportunities to access health care when you need it for a <u>physical health</u> problem?** *[Show response card 3]*	1 = terrible 2 = displeased 3 = mostly dissatisfied 4 = mixed 5 = mostly satisfied 6 = pleased 7 = delighted ☐
scope37	**How do you <u>feel</u> about your opportunities to access health care when you need it for a <u>mental health</u> problem?** *[Show response card 3]*	1 = terrible 2 = displeased 3 = mostly dissatisfied 4 = mixed 5 = mostly satisfied 6 = pleased 7 = delighted ☐

Your family and friends…

scope38	**Are either of your parents alive?**	2 = yes 1 = no (move to **Q40**) ☐
scope39	How often are you in contact with your parents?	4 = Once a week or more 3 = Once a month 2 = Several times a year 1 = Once a year or less 0 = Never/ Almost never ☐
scope40	**How do you <u>feel</u> about opportunities for contact with your family?** *[Show response card 3]*	1 = terrible 2 = displeased 3 = mostly dissatisfied 4 = mixed 5 = mostly satisfied 6 = pleased 7 = delighted ☐
scope41	**How many people would you call a friend?** (do not include family or health professionals)	Enter number in box ☐☐
scope42	**How often do YOU have friends or neighbours round to your house?** *[Read out options]*	6 = Every day 5 = Several times a week 4 = At least once a week 3 = At least once a fortnight 2 = At least once a month 1 = Less than once a month 0 = Never ☐

scope43	**How do you <u>feel</u> about <u>your</u> opportunities for contact with your friends and neighbours?** *[Show response card 3]*	1 = terrible 2 = displeased 3 = mostly dissatisfied 4 = mixed 5 = mostly satisfied 6 = pleased 7 = delighted ☐
scope44	**Overall, how do you <u>feel</u> about the extent to which you are included in society?** *[Show response card 3]*	1 = terrible 2 = displeased 3 = mostly dissatisfied 4 = mixed 5 = mostly satisfied 6 = pleased 7 = delighted ☐
scope45	Q45 excluded (obtain from socio-demographics section, if required)	
scope46	Q45 excluded (obtain from socio-demographics section, if required)	
scope47	Q47 excluded (obtain from socio-demographics section, if required)	
scope48	Q48 excluded (obtain from socio-demographics section, if required)	

SECTION 6: HEALTH RELATED QUALITY OF LIFE (EQ-5D)

EuroQol (1990). EuroQol - a new facility for the measurement of health-related quality of life. *Health Policy,* 16**,** 199-208.

When completing this section the patient should be given a copy of the EQ-5D and asked to complete it (**available on the last page of this booklet**).

The boxes on this page should be rated retrospectively using the EQ-5D completed by the patient.

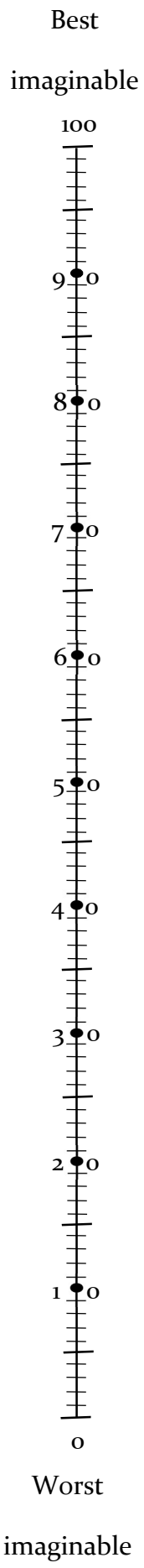
mobility_t5	*Mobility*	*1= I have no problems in walking about* *2= I have some problems in walking about* *3= I am confined to bed*	☐
selfcare_t5	*Self-Care*	*1= I have no problems with self-care* *2= I have some problems washing or dressing myself* *3= I am unable to wash or dress myself*	☐
activity_t5	*Usual Activities (e.g. work, study, housework, family or leisure activities)*	*1= I have no problems with performing my usual activities* *2= I have some problems with performing my usual activities* *3= I am unable to perform my usual activities*	☐
pain_t5	*Pain/Discomfort*	*1= I have no pain or discomfort* *2= I have moderate pain or discomfort* *3= I have extreme pain or discomfort*	☐
anxiety_t5	*Anxiety/Depression*	*1= I am not anxious or depressed* *2= I am moderately anxious or depressed* *3= I am extremely anxious or depressed*	☐
state_t5		*Health State*	☐☐☐☐☐

eqmeas_t5	*Scale measurement (page 38)*	☐☐☐

To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by **drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is today**

Your own health state



SECTION 7: PATIENT CAPABILITIES QUESTIONNAIRE (OXCAP-MH)

Simon, J., Anand, P., Gray, A., Rukasa, J., Yeeles, K., & Burns, T. (submitted). Operationalising the capabilities approach for outcome measurement in mental health studies. Social Science and Medicine.

Tell patient: *This questionnaire asks about differences aspects of your life*

pcq1_t5	**1**	**Does your health in any way limit your daily activities, compared to most people of your age?**	1 = Yes 2 = No ☐
pcq1a_t5	**1a**	**In response to <u>Question 1</u> above, please select one of the following further options:**	1 = Always 2 = Most of the time 3 = Some of the time 4 = Hardly ever 5 = Never ☐
pcq2_t5	**2**	**Are you able to meet socially with friends or relatives?**	1 = Yes 2 = No ☐
pcq2a_t5	**2a**	**In response to Question 2 above, please select one of the following further options:**	1 = Always 2 = Most of the time 3 = Some of the time 4 = Hardly ever 5 = Never ☐
pcq3_t5	**3**	**In the past 4 weeks, how often have you lost sleep over worry?** *[Show response card 5]*	1 = Always 2 = Most of the time 3 = Some of the time 4 = Hardly ever 5 = Never ☐
pcq4_t5	**4**	**In the past 4 weeks, how often have you been able to enjoy your recreational activities?** *[Show response card 5]*	1 = Always 2 = Most of the time 3 = Some of the time 4 = Hardly ever 5 = Never ☐
pcq5_t5	**5**	**How suitable or unsuitable is your accommodation for your current needs?** *[Show response card 6]*	1 = Very suitable 2 = Fairly suitable 3 =Neither suitable nor unsuitable 4 = Fairly unsuitable 5 = Very unsuitable ☐
pcq6_t5	**6**	**Please indicate how safe you feel walking alone in the area near your home:** *[Show response card 7]*	1 = Very safe 2 = Fairly safe 3 = Neither safe nor unsafe 4 = Fairly unsafe 5 = Very unsafe ☐

pcq7_t5	7	**Please indicate how likely you believe it to be that you will be assaulted in the future (including sexual and domestic assault):** *[Show response card 8]*	1 = Very likely 2 = Fairly likely 3 = Neither likely nor unlikely 4 = Fairly unlikely 5 = Very unlikely
pcq8a_t5	8A	**How likely do you think it is that you will experience discrimination?** *[Show response card 8]* **If 4 or 5, go to 8B**	1 = Very likely 2 = Fairly likely 3 = Neither likely nor unlikely 4 = Fairly unlikely 5 = Very unlikely
pcq8b_1_t5 pcq8b_2_t5 pcq8b_3_t5	8B	**On what grounds do you think it is likely that you will be discriminated against?** (*Please complete only if your answer to question 8A is 'Very likely' or 'Fairly likely, otherwise score 888)* *[Show response card 9]* **Please select up to <u>three</u> (score unselected 888)**	1 = Race/ethnicity 2 = Gender 3 = Religion 4 = Sexual orientation 5 = Age 6 = Health or disability (including mental health)

9 Please indicate how strongly you agree or disagree with the following statements:

[Show response card 10]

			Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
pcq9a_t5	9A	**I am able to influence decisions affecting my local area.**	1	2	3	4	5
pcq9b_t5	9B	**I am free to express my views, including political and religious views.**	1	2	3	4	5
pcq9c_t5	9C	**I am able to appreciate and value plants, animals and the world of nature.**	1	2	3	4	5
pcq9d_t5	9D	**I respect, value and appreciate people around me.**	1	2	3	4	5
pcq9e_t5	9E	**I find it easy to enjoy the love, care and support of my family and friends.**	1	2	3	4	5
pcq9f_t5	9F	**I am free to decide for myself how to live my life.**	1	2	3	4	5
pcq9g_t5	9G	**I am free to use my imagination and to express myself creatively (e.g. through art, literature, music, etc.).**	1	2	3	4	5

pcq9h_t5	**9H**	**I have access to interesting forms of activity (or employment).**	1	2	3	4	5
	10	**The next question asks you to think about your life expectancy:** The average life expectancy in the UK is 77 years for men and 81 years for women. Some people think they are going to live longer than the average person whilst other people believe they are going to live shorter than the average person.					
pcq10a_t5	**10 A**	**Given your family history, dietary habits, lifestyle and health status, do you expect to live ….?**	1 = Longer than average 2 = Same as average 3 = Shorter than average ☐				
pcq10b_t5	**10 B**	**Until what age do you believe you are going to live?** (*Please complete only if your answer to question 10A is 'Longer than average' or 'Shorter than average'.)*	☐☐☐ years				
pcq11_t5	**11**	**How satisfied or dissatisfied are you with your life as a whole?** *[Show response card 12]*	1 = Completely satisfied 2 = Very satisfied 3 = Fairly satisfied 4 = Neither satisfied nor dissatisfied ☐ 5 = Fairly dissatisfied 6 = Very dissatisfied 7 = Completely dissatisfied				

INSTRUCTIONS: This section to be completed independently by participant

SECTION 8: ICECAP CAPABILITY MEASURE FOR ADULTS (ICECAP-A)

Al-Janabi, H., Flynn, T. N. & Coast, J. (2012). Development of a self-report measure of capability wellbeing for adults: the ICECAP-A. Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation, 21, 167-176.

Please indicate which statements best describe your overall quality-of-life at the moment
Please ensure that you tick only ONE box for each of the five groups

ice_1	**1. Feeling settled and secure**		
	I am able to feel settled and secure in **all** areas of my life	☐	4
	I am able to feel settled and secure in **many** areas of my life	☐	3
	I am able to feel settled and secure in **few** areas of my life	☐	2
	I am **unable** to feel settled and secure in **any** areas of my life	☐	1

ice_2	**2. Love, friendship and support**		
	I can have **a lot** of love, friendship and support	☐	4
	I can have **quite a lot** of love, friendship and support	☐	3
	I can have **a little** love, friendship and support	☐	2
	I cannot have **any** love, friendship and support	☐	1

ice_3	**3. Being independent**		
	I am able to be **completely** independent	☐	4
	I am able to be independent in **many** things	☐	3
	I am able to be independent **in a few** things	☐	2
	I am **unable** to be at all independent	☐	1

ice_4	**4. Achievement and progress**		
	I can achieve and progress in **all** aspects of my life	☐	4
	I can achieve and progress in **many** aspects of my life	☐	3
	I can achieve and progress in **a few** aspects of my life	☐	2
	I **cannot** achieve and progress in **any** aspects of my life	☐	1

ice_5	**5. Enjoyment and pleasure**		
	I can have **a lot** of enjoyment and pleasure	☐	4
	I can have **quite a lot** of enjoyment and pleasure	☐	3

SECTION 9: ADMISSION EXPERIENCE SURVEY (AES)

Gardner, W., Hoge, S. K., Bennett, N., Roth, L. H. & et al., (1993). Two scales for measuring patients' perceptions for coercion during mental hospital admission. Behavioral Sciences & the Law, 11, 307-321.

Now let's get back to you and your experiences of treatment. Think back over your experience of contact with the mental health team over the past six months. Think about all of the things people might have done to keep you in contact with the team or taking medications as prescribed. Then tell me how you feel about the following statements. Do you…

[show response card 13]

		Strongly agree	Agree	Neutral/ Mixed	Disagree	Strongly disagree
coerc1_t5	**I felt free to do what I wanted about seeing my care coordinator**	1	2	3	4	5
coerc2_t5	**People tried to force me to see my care coordinator**	1	2	3	4	5
coerc3_t5	**I had enough of a chance to say whether I wanted to see my care coordinator**	1	2	3	4	5
coerc4_t5	**I chose to see my care coordinator**	1	2	3	4	5
coerc5_t5	**I got to say what I wanted about seeing my care coordinator**	1	2	3	4	5
coerc6_t5	**Someone threatened me to get me to see my care coordinator**	1	2	3	4	5
coerc7_t5	**It was my idea to see my care coordinator**	1	2	3	4	5
coerc8_t5	**Someone physically tried to make me see my care coordinator**	1	2	3	4	5
coerc9_t5	**No one seemed to want to know whether I wanted to see my care coordinator**	1	2	3	4	5
coerc10_t5	**I have been threatened with sectioning**	1	2	3	4	5
coerc11_t5	**They said they would make me see my care coordinator**	1	2	3	4	5
coerc12_t5	**No one tried to force me to see my care coordinator**	1	2	3	4	5
coerc13_t5	**My opinion about going to see my care coordinator didn't matter**	1	2	3	4	5
coerc14_t5	**I had a lot of control over whether I saw my care coordinator**	1	2	3	4	5
coerc15_t5	**I had more influence than anyone else on whether I saw my care coordinator**	1	2	3	4	5

SECTION 10: BRIEF PSYCHIATRIC RATING SCALE (BPRS)

Overall, J. E. & Gorham, D. R. (1962). The Brief Psychiatric Rating Scale. Psychological Reports, 10, 799-812.

Time frame: past 2 weeks

		Nil/not assessed	Not present	Very Mild	Mild	Moderate	Moderate/ severe	Severe	Extremely Severe
bprs1 _t5	**Somatic Concern**	777	1	2	3	4	5	6	7
bprs2 _t5	**Anxiety**	777	1	2	3	4	5	6	7
bprs3 _t5	**Depression**	777	1	2	3	4	5	6	7
bprs4 _t5	**Suicidality**	777	1	2	3	4	5	6	7
bprs5 _t5	**Guilt**	777	1	2	3	4	5	6	7
bprs6 _t5	**Hostility**	777	1	2	3	4	5	6	7
bprs7 _t5	**Elevated Mood**	777	1	2	3	4	5	6	7
bprs8 _t5	**Grandiosity**	777	1	2	3	4	5	6	7
bprs9 _t5	**Suspiciousness**	777	1	2	3	4	5	6	7
bprs10 _t5	**Hallucinations**	777	1	2	3	4	5	6	7
bprs11 _t5	**Unusual Thought Content**	777	1	2	3	4	5	6	7
bprs12 _t5	**Bizarre Behaviour**	777	1	2	3	4	5	6	7
bprs13 _t5	**Self-Neglect**	777	1	2	3	4	5	6	7
bprs14 _t5	**Disorientation**	777	1	2	3	4	5	6	7

Rate items 15-124 on the basis of observed behaviour or speech pattern during the interview.

bprs15 _t5	**Conceptual Disorganisation**	777	1	2	3	4	5	6	7
bprs16 _t5	**Blunted Affect**	777	1	2	3	4	5	6	7
bprs17 _t5	**Emotional Withdrawal**	777	1	2	3	4	5	6	7
bprs18 _t5	**Motor Retardation**	777	1	2	3	4	5	6	7
bprs19 _t5	**Tension**	777	1	2	3	4	5	6	7
bprs20 _t5	**Uncooperativeness**	777	1	2	3	4	5	6	7
bprs21 _t5	**Excitement**	777	1	2	3	4	5	6	7
bprs22 _t5	**Distractibility**	777	1	2	3	4	5	6	7
bprs23 _t5	**Motor Hyperactivity**	777	1	2	3	4	5	6	7
bprs24 _t5	**Mannerisms and Posturing**	777	1	2	3	4	5	6	7

For researchers' BPRS notes:

Somatic Concern	Conceptual Disorganisation
Anxiety	Blunted Affect
Depression	Emotional Withdrawal
Suicidality	Motor Retardation
Guilt	Tension
Hostility	Uncooperativeness
Elevated Mood	Excitement
Grandiosity	Distractibility
Suspiciousness	Motor Hyperactivity
Hallucinations	Mannerisms and Posturing
Unusual Thought Content	**GAF NOTES**
Bizarre Behaviour	
Self-Neglect	Disorientation ☐ Date ☐ Location ☐ Prime Minister

SECTION 11: GLOBAL ASSESSMENT OF FUNCTIONING (GAF)

Time Frame: past 2 weeks

Domain	Symptom Severity	Level of Functioning
1-10	Persistent danger of severely hurting self or others (e.g. recurrent violence) or serious suicidal act with clear expectation of death.	Persistent inability to maintain minimal personal hygiene
11-20	Some danger of hurting self or others (e.g. suicide attempts without clear expectation of death; frequently violent; manic excitement).Gross impairment in communication (e.g. largely incoherent or mute)	Occasionally fails to maintain minimal personal hygiene (e.g. smears faeces)
21-30	Behaviour is considerably influenced by delusions or hallucinations or serious impairment in communication or judgment (e.g. sometimes incoherent, acts grossly inappropriately, suicidal preoccupation)	Inability to function in almost all areas (e.g. stays in bed all day, no job, home or friends)
31-40	Some impairment in reality testing or communication (e.g. speech is at times illogical, obscure or irrelevant)	Major impairment in several areas, such as work or school, family relations, judgment, thinking, or mood (e.g. depressed man avoids friend, neglects family, and is unable to work; child frequently beats up younger children, is defiant at home and is failing in school).
41-50	Serious symptoms (e.g. suicidal ideation, severe obsessional rituals, frequent shoplifting).	Any serious impairment in social, occupational, or school functioning (e.g. no friends, unable to keep a job).
51-60	Moderate symptoms (e.g. flat affect and circumstantial speech, occasional panic attacks)	Moderate difficulty in social, occupational, or school functioning (e.g. few friends, conflicts with co-workers).
61-70	Some mild symptoms (e.g. depressed mood and mild insomnia)	Some difficulty in social, occupational or school functioning (e.g. occasional truancy, or theft within the household), but generally functioning pretty well, has some meaningful interpersonal relationships.
71-80	If symptoms are present, they are transient and expectable reactions to psychosocial stressors (e.g. difficulty concentrating after family argument).	No more than slight impairment in social, occupational, or school functioning (e.g. temporarily falling behind in school work).
81-90	Absent or minimal symptoms (e.g. mild anxiety before an exam). Generally satisfied with life. No more than everyday problems or concerns (e.g. an occasional argument with family members).	Good functioning in all areas, interested and involved in a wide range of activities, socially effective.
91-100	No symptoms	Superior functioning in a wide range of activities, life's problems never seem to get out of hand. Is sought out by others because of his or her many positive qualities
Gaf _t5		**GAF Score** ☐☐☐

By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.

Mobility

I have no problems in walking about ❑

I have some problems in walking about ❑

I am confined to bed ❑

Self-Care

I have no problems with self-care ❑

I have some problems washing or dressing myself ❑

I am unable to wash or dress myself ❑

Usual Activities (*e.g. work, study, housework, family or leisure activities)*

I have no problems with performing my usual activities ❑

I have some problems with performing my usual activities ❑

I am unable to perform my usual activities ❑

Pain/Discomfort

I have no pain or discomfort ❑

I have moderate pain or discomfort ❑

I have extreme pain or discomfort ❑

Anxiety/Depression

I am not anxious or depressed ❑

I am moderately anxious or depressed ❑

I am extremely anxious or depressed ❑

Appendix II: Floor and ceiling effects for OxCAP-MH

Table I: Floor and ceiling effects for OxCAP-MH items scored on a 1 to 5 Likert scale

Item	Floor	Ceiling
1. Does your health limit your daily activities	n/a	n/a
2. Able to meet socially with friends and relatives	n/a	n/a
3. In past 4 weeks, how often lost sleep over worry	43%*	2%
4. In the past 4 weeks, how often able to enjoy recreational activities	10%	12%
5. Suitable / Unsuitable accommodation for current needs	7%	42%*
6. How safe feel walking alone near home	5%	43%*
7. Able to influence decisions affecting local area	6%	11%
8. Free to express views	10%	4%
9. Able to appreciate and value plants, animals and world of nature	28%	1%
10. Respect, value and appreciate people around me	26%	1%
11. I find it easy to enjoy the love, care and support of my family	27%	4%
12. Free to decide how to live life	12%	6%
13. Free to use imagination and express myself creatively	14%	4%
14. Have access to interesting forms of activity or employment	11%	5%
15. How likely will be assaulted in future	39%	6%
16. How likely will experience discrimination	31%	12%

* Denotes floor / ceiling effect (>40%)

Appendix III: OxCAP-MH individual item correlations

Table II: Correlation of individuals items of the OxCAP-MH with established measures of illness severity, functioning and social outcomes

	OxCAP-MH individual items†							
	Item 1	*Item 2*	*Item 3*	*Item 4*	*Item 5*	*Item 6*	*Item 7*	*Item 8*
EQ-5D 3L	.457**	.270**	.346**	.197**	.109	.206**	.080	.101
EQ-5D VAS	.473**	.320**	.183*	.225**	.236**	.167*	.076	.274**
BPRS	-.338**	-.170*	-.453**	-.173*	-.238**	-.226**	-.043	-.158*
GAF	.266**	.092	.131	.109	.013	.148	.069	.044
SIX	-.016	.170*	.057	.008	-.015	.050	.054	.055
	Item 9	*Item 10*	*Item 11*	*Item 12*	*Item 13*	*Item 14*	*Item 15*	*Item 16*
EQ-5D 3L	.023	.031	.215**	.243**	.264**	.199**	.271**	.269**
EQ-5D VAS	.124	.082	.307**	.286**	.330**	.287**	.272**	.277**
BPRS	-.064	.031	-.228**	-.161*	-.254**	-.173*	-.231**	-.248**
GAF	.078	.017	.273**	.137	.073	.163*	.089	.076
SIX	.147	.173*	.150	.029	.006	.113	.046	.018

EQ-5D 3L = Euro-Qol 3 level; EQ-5D VAS = Euro-Qol Visual Analogue Scale; BPRS = Brief Psychiatric Rating Scale; GAF = Global Assessment of Functioning; SIX = Objective Social Outcomes Index

† See Appendix I, Section 7, for precise wording of individual items

*** Significant at the .001 level * Significant at the .05 level*

Statistically significant correlations between individual items in the OxCAP-MH and established outcome measures. Significant correlations were observed between item 1 (health and daily activities) and the EQ-5D utility scores (0.46, $p < .001$), EQ-5D VAS (0.47, $p < .001$), BPRS (-0.34, $p < .001$) and GAF (0.27, $p < .001$), but not the SIX (-.02, p

= ns). One would expect this item to be associated with measures of symptom severity and functioning but not necessarily with social outcomes.

END