THE CARE PATHS OF YOUNG PEOPLE REFERRED BUT NOT ADMITTED TO INPATIENT CHILD AND ADOLESCENT MENTAL HEALTH SERVICES

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DECLARATIONS OF INTEREST

None

The appendices below are attached separately

A 3 DATA COLLECTION TOOLS

A4 RELATED PAPERS

A 4.1 Meenaghan, A., O'Herlihy, A., Durand, M A., Farr, H., Tulloch, S., Lelliott, P (2007) A 55 kg paper mountain: The impact of new research governance and ethics processes on mental health services research in England. *Journal of Mental Health,* 16(1): 149-155.

A 4.2 O' Herlihy A, Lelliottt P, Bannister D, Cotgrove A., Farr, H and Tulloch, S. (2007) Provision of child and adolescent mental health in-patient services in England between 1999 and 2006. *Psychiatric Bulletin*, 31: 454-456.

A 5 OUTLINE OF CAMHS FOR TWO OF THE FOUR SHA AREAS

FIGURES   TITLE   PAGE

Abbreviations	
AMHS	Adult Mental Health Services
CAMHS	Child and Adolescent Mental Health Service
CGAS	Children's Global Assessment Scale
Children's NSF	National Service Framework for Children, Young People and Maternity Services (2004)
CHYPIE	Children and Young Peoples' Inpatient Evaluation
CMHT	Community Mental Health Team
CSIP	The Care Standards Improvement Partnership
DH	Department of Health
GAU	General Adolescent Unit
HAS	Health Advisory Service
HCC	Healthcare Commission
HoNOSCA	Health of the Nation Outcomes Scales for Children and Adolescents
IP	Inpatient
MHAC	Mental Health Act Commission
NICAPS	National Inpatient Child and Adolescent Psychiatry Study
NICE	National Institute of Health and Clinical Excellence
NIMHE	National Institute for Mental Health in England
NSF	National Service Framework
ONS	Office of National Statistics
PSA	Public Sector Agreement
QNIC	Quality Network for Inpatient CAMHS
SHA	Strategic Health Authority
Notes for terminology	
Young people	Refers to the adolescent age group.
IP CAMHS	Refers to inpatient CAMHS unit.
Units	The term 'unit' is used in place of IP CAMHS to avoid repetition.

1. EXECUTIVE SUMMARY

1.1 Introduction and aims

The Government has pledged to meet the mental health needs of all young people and committed to put in place comprehensive child and adolescent mental health services (CAMHS) by 2006. Inpatient (IP) mental health care is an important part of this provision. Despite this, there is some evidence that a proportion of young people who are referred to IP CAMHS are denied admission because of a lack of available beds in an appropriate setting. One consequence of this is that at least one-third of all admissions of young people for the treatment of a mental disorder are to an adult psychiatric ward or paediatric ward. The new amendments to the 1983 Mental Health Act (Mental Health Act, 2007-Section 31) require that, in future, young people are only admitted to an age appropriate environment.

The original aims of the study were to examine:

- the demand for adolescent CAMHS beds in areas of England with high and low provision of IP CAMHS;
- the reasons for admission and non-admission;
- the care paths followed by those not admitted;
- the experience of young people who are not admitted and of their parents;
- the factors that influence decisions to admit;
- the extent of consensus about criteria that constitute 'appropriateness' for admission.

1.2 Methods

Changes to the research governance and research ethics approval procedures, introduced in 2004 caused delays and forced us to change the original research methods. The final study had three components:

1. Information collected from clinicians, by questionnaire, about adolescents (12 to 18 year olds) referred over a six-month period to inpatient CAMHS from two Strategic Health Authority (SHA) areas: one in the East of England which had low provision of inpatient CAMHS (12.2 beds per million population) and one in London which had high provision (43.1 beds per million population). The terms 'high' and 'low' provision are used to be consistent with the recommendation by the Royal College of Psychiatrists that 20 to 40 beds are required per million population (Royal College of Psychiatrists, 2005).

2. Structured telephone interviews with professionals to track the care paths of those young people that were not admitted.

3. The identification of criteria for what constitutes 'appropriateness' for admission. This involved a literature review and a consensus forming exercise involving CAMHS professionals working in both community and inpatient settings.

1.3 Main findings

We identified 159 referral episodes involving 143 young people in the two SHA areas and obtained detailed questionnaire data about the young people who were the subject of 105 of these referral episodes, 67 of which resulted in an admission.

1.3.1 Referrals to inpatient CAMHS from the two SHA population bases

- The rate of referral in London was more than twice that in the East (90 vs 39 per 100,000 population of 12-18 year olds).
- The group referred in London contained a higher proportion of both younger children, age 12-13 ($z=2.99$; $p<0.01$) and older adolescents, age 16-17 ($z=4.81$; $p<0.001$) than did the East SHA area.

1.3.2 Referral pattern and outcomes for the 159 referral episodes

During the referral episode, 121 young people were referred to a single unit, 31 were referred to two units and 7 to three or more units. One hundred out of the 159 referral episodes resulted in an admission (63% of the total number of referral episodes).

The pattern was for the first referral to be to an NHS unit within the region, followed by onward referral to an independent sector unit within the region and then to an independent sector unit outside of the region. A higher proportion of all referrals to independent sector units resulted in an admission than did those to the NHS (62 of 73 vs 38 of 133; $z= 7.42$, $p<0.001$). Sixty-two of the 100 admissions were to an independent sector unit.

Eleven of the 44 young people from the East SHA, who were admitted, were admitted to a unit outside their region compared with just one of the 55 young people from London who were admitted. All of those referred to an NHS specialist eating disorder unit were from within the Eastern Region (n=23) and seven were admitted. Only one young person in London was referred and admitted to an independent sector eating disorder unit within the London Region. There were no significant differences between the East and London SHA in:

- the proportion of young people who were subsequently referred on to another unit after not being admitted to the first (23% in London compared with 25% in the East);
- the proportion admitted to the <u>first</u> unit referred to (44% in London compared with 37% in the East);
- the proportion admitted to any unit during the study period (64% in London compared with 62% in the East);
- the proportion <u>not</u> admitted to any unit (34% in London compared with 37% in the East).
- the proportion of young people whose admission was to an independent sector unit (66% in the East compared with 59% in London).

1.3.3 Outcome of emergency referrals

The referrer had requested an emergency admission for 41 of the 67 young people for whom full questionnaire data were obtained and who were admitted as a result of the referral episode. Of these, 20 were admitted to the first unit to which they were referred. Of the 21 emergency referrals that had to be referred

on to another unit after being denied access to the first, nine young people had to wait between two and seven days for a bed to be found.

1.3.4 Comparison of those admitted with those not admitted

Compared with those not admitted, the group of young people who were admitted:

- were more often referred as an emergency (Fisher's exact test: $p < 0.0001$);
- had more severe problems (mean CGAS 33 compared with 41);
- were 13 times more likely to have attempted suicide (odds ratio: 12.9; $p < 0.05$).

1.3.5 Comparison of those referred from the East and from London SHA

Compared with those from the East SHA, the group of young people referred from the London SHA:

- contained a higher proportion of young people from black and minority ethnic groups (31% in London vs 6% in the East; Chi=12.69; $p < 0.001$).
- contained a lower proportion of young people with an eating disorder (5% vs 39%; Chi=15.65; $p < 0.001$).
- had more severe problems (mean CGAS score of 32 vs 39; Mann Whitney U Test $p < 0.05$). This difference was accounted for by the higher proportion of young people with an eating disorder in the East SHA.
- contained a higher proportion of young people who had experienced some form of abuse (Chi=8.5 $p < 0.05$).

1.3.6 Factors that influenced the decision to refer for admission

The main reason for referral was severity of presenting problems and risk to self and others (first reason for 80 of the 105 young people and the second reason for a further 13). Other factors considered important (ranked first, second or third reason for referral) for a substantial number of young people were:

- the young person was not responding to out-patient treatment (n=38);
- the need for a full psychiatric assessment in a controlled environment (n=22);
- the ability of the family to cope (n=18).

1.3.7 Reasons why young people were not admitted

For those not admitted to any unit (n=38), the main reasons for not being admitted to the first unit to which they were referred were because the young person:

- or their parent refused an offer of a place (n = 22);
- was assessed as not needing IP CAMHS care (n=9);
- improved after an assessment or while awaiting assessment or admission (n=5);
- required admission to a paediatric ward because of low weight (n=2).

The reasons for not being admitted to the first unit to which they had been referred for those who were referred on and subsequently admitted to another unit (n=31) were:

- no bed was available (n=22);
- the young person or their relatives refused admission (n=4);
- the young person was approaching the age limit of the unit (n=1);
- the unit could not offer admission soon enough (n=1).

1.3.8 Contact with services before and after referral episode

The young people referred for admission made heavy use of services both during the six months before referral and during the six months after referral. This was true whether they were admitted as a result of the referral or not. The general pattern was for young people to have had contact with multiple different agencies or professionals both before and after referral – a mean of three (range 0-8 different services/ professionals).

Nine of the 105 young people were admitted to an adult mental health ward during the six months before the referral episode and nine in the six months following it (one young person was admitted both before and after the referral episode). Twelve of the 17 young people who were admitted to an adult ward were female.

1.3.9 Consensus among clinicians for determinants for admission

The criteria ranked first and second in the consensus exercise to determine criteria for admission both concerned risk to self – *"risk of suicide"* and *"physical health is deteriorating due to mental illness".* Other factors rated as important by more that 80% of the participants were:

- need for 24-hour a day observation to develop a care plan;
- presence of serious self-harm;
- unresponsive to outpatient care;
- young person's willingness or desire to engage in treatment package.

1.4 Conclusions

1. The higher overall referral rate in London is probably due to greater need for CAMHS inpatient care rather than because demand is being driven by a greater supply of beds.

2. The higher rate of referral in the East of young people with an eating disorder is probably influenced by the presence of an NHS eating disorders unit in the region.

3. The higher rate of admission to units outside of the region in the East is probably partly due to the relatively low number of beds in the region.

4. Nearly two-thirds of all admissions were to units managed by the independent sector which acts as a "sump" for onward referrals from NHS units that cannot offer a bed.

5. Independent sector units are much less likely to turn away a referral than are NHS units.

6. Emergency admissions are being delayed because of problems of bed availability in NHS units. This is contrary to the Government's PSA target (Department of Health, 2004; Department of Health and the Department for Education and Skills, 2006) and expectations that local service commissioners have in relation to improved access and greater choice, and is not consistent with the Department of Health's assertion that there is 24-hour cover for urgent needs or specialist assessments across the country (UK Government, 2007).

7. The young people who are not admitted have high levels of contact with services, including adult services, both before and after the referral episode.

8. A significant number of young people referred to CAMHS inpatient units have admissions to adult mental health wards before and/or after referral. In future, many such admissions are likely to be in breach of the Mental Health Act 2007 which requires that young people have access to appropriate care in an environment suited to their age and development.

9. Although our study numbers are small, in contrast to other surveys that show that more males under age 18 than females are admitted to adult wards, there was a preponderance of females in the group that were admitted to adult mental health wards. This might suggest that young men are more likely to by-pass referral to CAMHS inpatient care on their pathway into an adult ward.

10. Risk to self is by far the strongest factor that influences decisions to admit. Any service for young people that is established with the intention of preventing admissions must, first and foremost, provide care that reduces the risk of harm coming to the young person or at least is believed to do so by clinicians making referrals.

1.5 RECOMMENDATIONS

1. The Department of Health might develop the findings of this study by commissioning work to reach formal agreement with clinicians responsible for admission decisions about criteria that determine appropriateness of admission to IP CAMHS. This work might also be informed by the criteria developed by the Scottish Executive (2005). Criteria would include those relating to diagnosis/problem type and to a wide range of contextual factors. The latter would include risk posed to and by the young person, their social and family situation, and the availability or otherwise of community-based services that might act as an alternative to admission.

2. Once the criteria have been developed, clinicians working in both community and inpatient CAMHS should be encouraged to audit their practice in relation to local admission decisions. The audit should include both NHS and independent sector units.

3. The problem of delays in emergency admissions is likely to be compounded as demand increases due to pressure to implement the requirement of the Mental Health Act 2007 that young people are admitted to an age-appropriate setting. Unless the ability of NHS units to accept same day admissions, including out of hours, has greatly increased since this study, and a national survey conducted in 2005 (Cotgrove et al., 2007), most such admissions will be to independent sector units. Commissioners must ensure that procedures are in place to guarantee that adequate liaison occurs between the independent sector unit and local NHS services to ensure continuity of care for these very vulnerable young people.

4. Services that are developed as alternatives to admission must be capable of providing safe care to young people who are assessed as being at risk of self-harm and/or suicide if they are to substantially reduce demand for inpatient care.

5. To identify those most vulnerable to not accessing IP care, the Department of Health need to audit all those aged under 18 who present to other health settings (A&E departments, adult psychiatric or paediatric wards) and who require a psychiatric assessment. To inform planning it would be necessary to identify their routes into these settings and their prior, if any, contact with CAMHS and then track the care path they follow subsequent to the assessment. This group of young people should also be interviewed about their access to mental health services. This could be achieved through an audit and service evaluation project.

2. INTRODUCTION AND STUDY OBJECTIVES

2.1 INTRODUCTION

The Government has pledged to meet the mental health needs of all young people in England and committed itself to putting in "…*place comprehensive child and adolescent mental health services (CAMHS) by 2006*" (Department for Education and Skills, 2003). To achieve this goal standards have been set to ensure CAMHS care for young people, up to their 18th birthday, is provided on an equitable basis and close to the young person's home (Department of Health, 2004). Inpatient (IP) mental health care is an important part of this provision for young people with severe and complex mental health problems who require intensive, 24-hour psychiatric care in an age-appropriate environment with educational facilities. Recent research has described the characteristics of this group of young people (Jacobs et al., 2004; O'Herlihy et al., 2004).

Inpatient mental health provision for adolescents, although expensive, is effective (Blanz and Schmidt, 2000; Green et al., 2001; Jacobs et al., 2004; Kutash and Rivera, 1996; Pfieffer and Strzelecki, 1990) and one of the consistent predictors of a positive outcome is the level of engagement or therapeutic alliance achieved during admission (Green et al., 2001 & 2007). Despite these positive outcomes, some young people are denied admission due to a lack of available beds in an appropriate setting (Gowers et al., 2001; Mental Health Act Commission - MHAC, 2001; 2004; Worrall et al., 2004). The aim of this study is to identify what happens to adolescents who do not access IP CAMHS beds when referred. It also examines the extent to which there is agreement amongst clinicians about the factors that determine the need for admission.

This chapter summarises the context within which the research was conducted and describes the objectives of the study. It starts by describing the extent of the uneven and inadequate provision of IP CAMHS and the impact that may have, with particular reference to the admission of young people to alternative less appropriate forms of inpatient settings (paediatric wards and adult psychiatric wards). It then summarises the factors that influence the decision to admit to IP CAMHS; dividing these into those that relate to the patient and their circumstances and those that relate to the service. This leads on to a statement of the aims of the study.

2.2 BACKGROUND

A fuller description of the context for this study is given in appendix 1.0. What follows is a précis of this.

2.2.1 Evidence of inequitable provision

Reports over the past 20 years have commented on gaps in the provision of IP CAMHS. Two particular themes recur: difficulty with access to specialist inpatient care for adolescents, particularly those over the age of 16 years, and a lack of basic information about the availability and effectiveness of IP CAMHS to inform

future developments (Audit Commission, 1999; Health Advisory Service – HAS, 1986 & 1995; Kurtz et al., 1994; O'Herlihy et al., 2001 & 2003). In the late 1990s, the House of Commons Select Committee called on the Department of Health to prioritise research in this area. This resulted in the commissioning of a national review of inpatient CAMHS in 1999 (National In-patient Child and Adolescent Psychiatry Study – NICAPS, O'Herlihy et al., 2001) and research about its effectiveness in 2001 (the Children and Young People's Inpatient Evaluation-CHYPIE, Green et al., 2007; Jacobs et al., 2004). The NICAP study confirmed previous reports of 'patchy' provision and showed the extent to which beds are unevenly distributed across the regions in England and Wales (O'Herlihy et al., 2001 & 2003). NICAPS also found that for every four young people referred, three are assessed and two admitted. Some of those assessed as needing IP CAMHS were at times refused admission due to a lack of resource and/or the nature of their difficulties or willingness to engage (O'Herlihy et al., 2001). Since NICAPS, there has been an increase in the number of adolescent CAMHS beds in England accompanied by a 30% decrease in the number of beds for children under age 14 (O'Herlihy et al., 2007). However, despite this increase in adolescent beds the inequity has widened due to developments occurring in the regions with high bed provision and little or no change occurring in regions with low provision in 1999 (the terms 'high' and 'low' are used relative to the recommendation by the Royal College of Psychiatrists (2005) that there be between 20 and 40 beds per million population).

2.2.2 Lack of emergency provision

Surveys of those who refer to IP CAMHS units have reported a need for improved access, prompt response to emergencies (within 24 hours), and shorter waiting times (Gowers, Symington, and Entwistle, 1991; Steinberg, Galhenge, and Robinson, 1981; Worrall and O'Herlihy, 2001). Consistent with this, NICAPS found that two-thirds of the units did not admit young people within 24 hours, or provide an admission service outside of office hours (O'Herlihy et al., 2003). Two further surveys, one in 2000 and the second in 2005, indicate that units are adapting to this need for emergency access (Cotgrove et al., 2007). These surveys found that 16 of 79 IP CAMHS units had dedicated emergency admission beds in 2005 compared with six in 2000. However, although 46 of 70 units stated they were able to admit within 24-hours, their ability to do this was hindered by staff shortages, funding, and lack of bed availability (Cotgrove et al., 2007).

Emergency admissions can cause problems for units which admit young people with a wide range of diagnoses. These are the most common type of unit and are under pressure to be all things to all people (see Appendix A 1.0 for a description of the type of units that admit young people with mental health problems). As a result, Cotgrove (1997) suggested that emergency admission beds should be provided in separate acute units. Corrigall and Mitchell (2002), who managed the first unit of this kind in England, proposed and discussed the benefits of providing acute (short-stay) IP care within CAMHS. This model has recently been adopted by a number of English NHS trusts and five more acute short-stay units have opened (O'Herlihy et al., 2007). All are located next to a general purpose IP CAMHS unit to allow for easy transfer to a lower intensity of care and a longer length of stay if required; thereby maintaining emergency access to beds. Although these recent developments are encouraging, it remains the case that emergency beds are still not widely available across England.

2.2.3 Admissions to other settings

The NICAP study estimated that one-third of all admissions of young people (under 18 years of age) for mental health treatment are to adult psychiatric wards or paediatric wards (Worrall et al., 2004). This is perhaps a conservative estimate. Gowers et al., (2001) surveyed admissions of 12 to 20 year olds with a discharge diagnosis for a psychiatric disorder, over a two-year period (1996-1998) in two health authorities in the North West, a region with few CAMHS beds. They found that only 21 out of a total of 950 admissions were to a regional IP CAMHS unit. More than one-third of all admissions (n=355) were to adult mental health wards; all but 13 of these were of young people aged 16 years or over. The majority of those under age 16 (186 of 225) were admitted to a paediatric ward. However, other young people were admitted to beds in general medical wards and in some cases placed in accident and emergency departments where the 12-hour maximum trolley wait was breached (Gowers et al., 2001). The Mental Health Act Commission (MHAC) looked at admissions to CAMHS and adult mental health wards in 2003. Over an 18-month period 270 young people were detained under the Act on an adult ward (this is probably an under-estimate because 213 of these were reported for the last nine-months suggesting under-reporting during the initial stages of the study). During the same period, there were 319 young people admitted informally, 63% of whom were admitted to adult facilities compared to only 23% to inpatient CAMHS (MHAC, 2004). The MHAC (2004) concluded that these admissions were a direct result of a shortage of CAMHS beds and a lack of emergency provision.

Acute adult psychiatric wards can be a disturbing environment in which to reside. These wards often provide a poor experience of care for those admitted; with high levels of disturbance with frequent incidents of assault. This often causes young people to feel unsafe (Barker, 2000; MILMIS Project Group, 1995; Office of the Children's Commissioner, 2007; Quirk and Lelliott, 2001; Scott, McGilloway and Donnelly, 2001; Worrall et al., 2004). Furthermore, adult wards often: i. lack policies to protect young people's safety and interests; ii. sometimes employ staff who have not been police vetted and iii. have no access to education facilities (MHAC, 2004, page 18). These were exactly the type of concerns that triggered the development of age-appropriate IP mental health care for adolescents more than 50 years ago (Cameron, 1949; Garralda, 1986; Parry Jones, 1995; Warren, 1952).

2.2.4 The characteristics of young people admitted to non IP CAMHS

The group of adolescents admitted to adult wards is older and contains a higher proportion of males than the group admitted to IP CAMHS, where two-thirds of young people admitted are female (Jacobs et al., 2004; O'Herlihy et al., 2004). In contrast, two-thirds of those detained under the Mental health Act in adult wards are male. Also, young people from black and minority ethnic groups are over-represented among those detained on adult wards, compared to admissions to CAMHS and the child census population data (see MHAC, 2004, page 22).

In the US and Australia, the age limits for admission to CAMHS and adult wards overlap (CAMHS up to 19 years and adult mental health 16 to 65). This allows for a more flexible choice about what service would best suit the young person's developmental status and maturity (Birleson, Luk and Mileshkin, 2001; McGorry, 1996). If the problems relating to staff, policies and education, identified by

MHAC, were addressed, this may be an option to consider in this country for some older adolescents.

2.2.5 Conclusion

There is good evidence that some young people who would benefit from care in IP CAMHS are instead admitted to other, less appropriate settings; in particular adult psychiatric wards. There is circumstantial evidence that young people admitted to adult wards differ from those admitted to CAMHS units (there are more 16-17 year olds, more males, more are from black and minority ethnic groups, and more are detained under the Mental Health Act). Nothing is known about those young people refused admission to IP CAMHS and what happens to their care when not admitted. For example are they subsequently admitted to an alternative healthcare residential setting?

2.3 RESEARCH CONTEXT

This is the first research study to explore what happens to those young people referred but not admitted to IP CAMHS. The principal aim is to examine the care paths taken by this group following non-admission. It is anticipated that this will inform service planners about gaps in provision and about the consequences for the care that these young people received subsequently.

IP CAMHS is an expensive resource. In an ideal world, it would be used by those young people with the greatest need and the greatest potential to benefit (Cotgrove, 2001; Green, 2002; Maskey, 1998) and access would be uniform across the country. If this was ever the case, it is possible that some young people who would benefit would still be denied admission due to scarcity of beds. However, such rationing could be justified on the grounds that those who were filling the beds were all in greater need.

This study explores whether adolescents who would benefit from inpatient care are denied access to a bed. It is possible that a young person might be denied admission because the bed is occupied by another person who could have been treated as well, but less expensively, in a non-inpatient setting. Recent descriptions of IP CAMHS populations do show that, as a group, those using IP CAMHS have more severe and complex clinical and psychosocial problems than those using community CAMHS (O'Herlihy et al., 2004; Wrate et al., 1994). However, this tells us nothing about the extent to which decisions about individual referrals or admissions are made consistently or about the extent to which beds are used optimally.

At the heart of the question of optimal use of IP CAMHS is the issue of what defines an appropriate admission to IP CAMHS. In practice, admission decisions are influenced by organisational and service-level factors, as well as by patient-level factors. This will always be the case in the real world. There might also be a third factor that influences decisions to admit that relates to the nature of the "market" for inpatient care in which supply of IP CAMHS outstrips demand for admission. Because, unlike on adult acute admission wards, admission decisions to IP CAMHS are made by those managing the supply, the attitudes and preferences of those making assessments are also likely to affect the final decision. Furthermore, the incentive systems that affect these decisions might operate differently in the NHS and the independent sector.

One objective of this study is to identify what factors define a need for admission. Thus, although, in the real world, there is a complex interplay between patient-level factors, and organisational and service-level factors, it is important to start by considering the two separately for the purposes of this research. We start by briefly reviewing the literature about patient-level factors that determine when a young person needs, or will benefit from, admission. We then introduce the organisational and service-level factors that sometimes modify these decisions.

2.3.1 Which young people need or would benefit from admission to IP CAMHS?

Reports about admission criteria in the UK are mainly descriptive and are based on clinicians' experiences and, with the exception of one multi-site study (Wrate et al., 1994), describe the admission practice of single units (Ainsworth, 1984; Jaffa and Dezsery, 1989; Steinberg et al., 1981; Wells, 1989).

- high recurrent risk of acts of self-harm or suicide;
- significant, ongoing self-neglect (for example, poor personal hygiene, or significant reduction in eating that could be harmful to the physical health of the child or young person);
- a requirement for intensity of assessment or treatment and/or high level of supervision that is not available in tiers 2 or 3.

There has been some debate about the primacy of diagnosis in influencing admission decisions. The Scottish Executive (2005, appendix 6) states that "the purpose of a psychiatric inpatient unit for young people is to offer inpatient assessment and management to young people with severe and/or complex psychiatric disorders and when outpatient or day-patient care has ceased to be able to meet the needs of that young person. It must be better to admit to hospital than not to admit to hospital and a young people's psychiatric inpatient unit cannot replace good quality social work services or fill the gap in local child and adolescent mental health services." It emphasises the importance of diagnosis by emphasising that admission should be considered if "a young person is suffering from a severe ICD10 Axis 1 disorder (including psychotic disorder, affective disorder, eating disorder, obsessive compulsive disorder, neuropsychiatric disorders, psychosomatic disorders, and disorders of development including pervasive developmental disorders)."

Some place greater emphasis on the use of admission to clarify diagnosis in a 'controlled environment' as one of the main functions of an IP CAMHS unit (Green, 2002; Wrate et al., 1994). The Scottish Executive also takes account of the need to admit for assessment when there is difficulty in reaching a diagnosis due to the complexity of the case. Others have challenged this and argue that inpatient CAMHS offers a false environment and that an assessment and diagnosis in most cases is better undertaken in the community where the young person is presenting their problems (personal communication with CAMHS consultants).

2.3.1.2 Characteristics of the young person's circumstances that influence the decision to admit

In addition to patient-level factors many of the UK studies report that the need for assessment or treatment must combine with factors such as:

- the problem cannot be resolved or managed with out-patient treatment alone (Cotgrove and Gowers, 1999; Wrate et al., 1994);
- the ability of the family to cope (Hersov, 1994; Warren, 1952; Wolkind and Gent, 1987; Wrate et al., 1994);
- the willingness to engage in treatment and the motivation for change of the young person and sometimes of the family (Ainsworth, 1984; Cotgrove, 2001; Green, 2001).

The decision making process is complex and clinicians must consider a number of other factors when deciding whether to refer and/or admit. Also, it is important that each inpatient stay has clear aims and objectives that are shared with the young person and their family. The need for safety and treatment should be weighed against possible contra-indications or negative consequences of admission (Dalton, Muller and Forman, 1989; Gowers and Cotgrove, 2003; NICE, 2005):

Positive
- Will the young person benefit actively from such care?

Negative
- Will admission disrupt the young person's family relationships?
- Will removal from school and social environment create stigma?
- Will admission create dependency on the staff and the institution?
- Will admission result in the young person acquiring more symptoms or worsening of symptoms (e.g. self-harm) or behaviour reinforced such as 'contagion' among eating disorder patients?

Preventative
- Will admission reduce the likelihood of suicide?

2.3.1.3 How patient-level factors combine

In a review of CAMHS admission practices, Maskey (1998) concluded that there are "no absolute indications for IP care...rather there are combinations of factors that determine referrals and admissions". One multi-site study of admissions to four general IP CAMHS identified four reasons for admission of those with a diagnosis of a conduct disorder or emotional disorder but only two for young people with a primary diagnosis of schizophrenia, affective disorder and adjustment disorder (Wrate et al., 1994). In the US, empirical methods have been employed to examine how factors combine to predict hospitalisation. Suicidal tendencies are reported to be the strongest predictor but only in combination with other factors such as substance misuse or assaultative behaviour (Gutterman et al., 1993).

The patient and support factors that contribute to a decision to admit, that have been identified by the literature, are summarised in table A 1.4 in Appendix A 1.0.

2.3.1.4 Organisational and service level factors that influence admission decisions

Given the inequity in provision, service and organisational factors are likely to influence referral and admission decisions. This has been shown to be true in the US where admission thresholds differ according to the level of resources available (Bickman, Foster, and Lambert, 1996). Furthermore, many of the single unit studies emphasised that a unit's current capacity (which are influenced by staff skill mix and nurse to patient ratios) and the dependency

levels of other resident young people (Steinberg et al., 1981; Wells, 1989) will influence admission decisions. Failure to consider these service factors could lead to the collapse of the therapeutic programme (Steinberg et al., 1981).

In this country, the uneven distribution of provision and poor emergency access partly explain why some adolescents with mental health problems are admitted for treatment to settings other than IP CAMHS (Mental Health Act Commission, 2001 & 2004; Gowers et al., 2001; Worrall et al., 2004).

However, it is not just the availability of resources that explains variation in admission practice. The national policy that CAMHS provide care up to the age of 18 years (Department of Health, 2004) is interpreted differently across the country. CAMHS sometimes attach conditions to the admission of those over 16, such as being in full-time education or having a definite home base or accommodation (Corbett, 2004). Also, disputes can arise when social services are reluctant to fund accommodation if a young person is approaching an age of independence, or while a young person is resident in IP CAMHS. Conversely an IP CAMHS unit may not accept a young person unless they have accommodation outside the unit to which they can return after discharge, or go on weekend leave (personal communication with inpatient and community CAMHS teams). This can lead to further social exclusion for young people and further difficulty in accessing services. Discrepancies in age limits among other agencies such as education, social services and adult mental health services can also affect access to services and continuity of care.

2.3.2 Care paths and the views of those not admitted

The concept of 'pathways to care' offers a way of exploring the use of health resources. One of the most cited models, the Goldberg and Huxley's (1980) filter model, is a framework to explain how people reach, and move through, mental health services, and this has been adapted for CAMHS by Verhulst and Koot (1992) and more recently by the Royal College of Psychiatrists (2005). The model assumes that individuals or in the case of young people their parents or carers, prompted by a desire to alleviate distress, move through a series of levels from community, primary care, through to secondary and tertiary health care. It has been argued that for young people the routes to care and mode of contact (formal and informal) can be varied, and delays more extensive than the model suggests (Lincoln and McGorry, 1995). This was confirmed by an examination of the pre-admission pathways to IP CAMHS in the CHYPIE study (Green et al., 2007; Jacobs et al., 2004). Many young people experienced significant delays prior to admission and parents reported that, at every stage, they viewed their child's problems as severe and found the referral to IP CAMHS helpful (Jacobs et al., 2004).

The focus for the application of the pathways model in CAMHS has been on the initial stages of treatment or first contact with services, rather than on the subsequent pathway (Gater and Goldberg, 1991; Gater et al., 2002;). Lincoln and McGorry (1995) emphasise the need to examine care pathways beyond the 'gateway'. They suggest employing a model that can consider the impact on the lives of those affected and how their future care paths are shaped. It has been argued that the quantitative methods employed in psychiatric medical research should be combined with qualitative methods to encompass the wide range of influences that impact on an individual's service use (Lincoln and McGorry, 1995; Morgan et al., 2004).

Thus, a model for IP CAMHS must account for the complexities and variations in an individual's care path, incorporate the views and experiences of the patient and family members including their willingness to accept care, and service level factors including the availability of other intensive levels of care in the community service (day patient programmes, intensive outreach, early onset psychosis teams, home-based treatment, multi systemic therapy and case management).

This study differs from other care path studies in that its primary focus is to examine the care young people receive post non-admission to an inpatient CAMHS unit. For this purpose a combination of quantitative and qualitative methods are employed.

2.4 RESEARCH QUESTIONS AND STUDY OBJECTIVES

This study required a population-based design to examine i. the demand for CAMHS from defined geographical areas and ii. the care paths followed by those adolescents referred for IP CAMHS but not admitted. It attempted to combine quantitative and qualitative methods to understand how the care paths affected young people and their parents or carers, and what their experiences were of the care received. The specific aims were to examine:

- the demand for adolescent CAMHS beds in areas of England with high and low provision of IP CAMHS relative to the numbers recommended by the Royal College of Psychiatrists (2005);
- the reasons for admission and non-admission;
- the care paths followed by those not admitted;
- young people and parents' experiences of the care paths followed;
- the extent of consensus about criteria that constitute 'appropriateness' for admission.

This study builds on the NICAPS findings and previous reports showing gaps in IP CAMHS, specifically for the adolescent population (12 to 18 years) in England. The study aimed to inform service planners about the characteristics of those not admitted, their contact with services post non-admission, and their views on the care received. Consensus for what criteria could determine admission was also obtained.

2.5 STRUCTURE OF THE REPORT

Chapter 3 describes the methods employed to address the study's aims. It also discusses problems caused by the research ethics and governance process that hindered the study. Chapter 4 reports on the results. Chapter 5 discusses the findings and lists the main conclusions that can be drawn from the study's data. Appendix 1.0 is the literature review. This has been placed here as opposed to in the introduction or discussion section to keep the body of the report short and accessible. The other appendices include the references, the data collection tools, and two related published papers.

3. METHODS

3.1 OVERVIEW

The protocol for the study describes four components:

- identification of young people referred and a questionnaire survey of clinicians to ascertain the characteristics of these young people;
- structured telephone interviews with professionals to track the care paths of those referred but not admitted;
- qualitative interviews with those not admitted;
- examination of the factors that influence decisions to refer and to admit, and exploration of what constitutes 'appropriateness' for admission.

Before describing the methods used, we first consider how national changes in the procedures for research ethics and research governance approvals affected the study design and the methods of data collection.

3.2 ETHICAL AND RESEARCH GOVERNANCE APPROVALS

The original protocol for this study, which was submitted for funding in September 2002, was based on that used in the earlier NICAP study which had been conducted by the same research team. The proposed methods met the research and governance rules that operated at that time. The protocol was based on two assumptions that had applied to NICAPS. First, that formal approval from NHS trusts would not be required for services to participate in the study, and second, that individual patient consent would not be required for the team to collect data about the characteristics and pathways of the young people referred. The latter was assumed because the data collected would be drawn from information collected as part of the routine clinical process; with the exception of the few young people who would have been interviewed and from whom informed written consent would have been obtained. Changes to both the research governance and ethics approval processes, made subsequent to the submission of the study protocol, meant that neither assumption held.

We have described the impact of these changes more fully elsewhere (Meenaghan et al., 2007-see Appendix 4.1) and present here a summary.

3.2.1 Research governance approval

New guidelines about local research governance procedures were implemented in April 2004. The research team first became aware in December 2003 that new regulations were to be introduced. At this time, the team had just engaged with services to set up the data collection system. The problem was compounded by

the fact that, not only had the rules changed, but, because we were undertaking the study at a time when trusts were adjusting to the new rules, there was no uniformity between trusts in the new systems that were being introduced. This caused one year's delay while the team obtained the agreements now required by the new procedures. Table 3.1 summarises the scale of the task. More detail is given in Appendix A 4.1. As a result, the first stage of data collection could not begin until November 2004, 12 months later than planned.

Table 3.1 The bureaucratic burden of obtaining research governance agreements

Total number of trusts invited to join the study	102
Number of research governance committees to which an application was submitted (some covered more than one trust)	62
Trusts using their own non-standardised application form	58
Trusts using the COREC Form C as substitute or supplement	0
Trusts using the COREC Form D as substitute or supplement	4
Trusts requiring additional supporting documents	All
Trusts requiring pre-approval from service manager	All
Trusts requiring honorary contracts	25
Average number of phone calls/emails/letters to each trust	9
Average number of pages per application pack to each trust	95
Additional time required	9 to 12 months

3.2.2 NHS research ethics approval and the impact of changes

The initial decision of the Trent mulit-centre research ethics committee (MREC) that reviewed the study was that no patient data could be collected without written consent from both the young person and their parent or carer if they were aged 18 or under. The required changes to the protocol created a 'Catch 22' situation. The researchers could not collect the information required to allow identification of the young person being referred. However, without this information, the team could not approach the young person to obtain their consent to collect the information required to identify them. Neither could the research team collect the information it would require to request a local healthcare professional to obtain consent on its behalf. After discussion with the MREC, the research team submitted an amendment, which was approved in November 2003. This specified a limited set of data items (the 'CIRS minimum dataset') that could be collected to facilitate the identification of referrals without consent:

- name of referrer
- name of unit referred to
- age in years/year of birth (not date of birth)

- gender
- diagnosis/presenting problems

However, even with this amendment, the process of securing consent proved arduous and slow. It could take up to ten months from the date of referral of a young person. Fortunately, by April 2005, MRECs had become more flexible in their interpretation of the new operational procedures. This was in response to concerns expressed by the research community that culminated in the review of research ethics commissioned by Lord Warner (Department of Health, 2005a); to which the research team submitted evidence drawn from this study.

Following submission of a further amendment, Trent MREC agreed that data could be collected without consent if they were '*fully anonymised at source by the NHS clinicians caring for the patient and no link was kept'*. This entailed removing the young person's initials and date of birth from the questionnaires. Approval for this amendment was finally obtained in August 2005.

This MREC amendment allowed for anonymised questionnaire and care path data to be collected without the need for consent. This had been the intention in the original study protocol. However, due to the delay, the study recruitment period (1 November 2004 to 30th of April 2005) had passed and it was no longer possible to collect the data prospectively, close to the time the clinician made the referral. Retrospective completion of the CIRS questionnaire still proved difficult because the research team was not permitted to collect any patient identifiers. This meant that the clinicians involved had to rely on the CIRS minimum dataset to identify a young person that they had referred for inpatient CAMHS treatment a year or more ago. When necessary, the research team assisted by arranging for the IP CAMHS unit to contact the referrer directly with the young person's name. Data collection was only possible once this identification had been made and the referrer had obtained the case notes of the young person concerned.

3.2.3 Other approval requirements

3.2.3.1 Approval from the Association of Directors for Social Services

Approval was sought and gained from the Association of Directors for Social Services in November 2003 to facilitate contact with social service professionals who may be the main contact for some young people during their subsequent care pathway.

3.2.3.2 Educational services

The researchers were advised to only contact the local education authority when required, i.e. if a participant was using specialist educational services during their care path.

3.3 SELECTION OF STUDY SITES

The unit of population (area) for the study was a Strategic Health Authority (SHA), as defined in 2003. Since SHAs are most likely to use CAMHS beds within their own region, areas were selected on the basis of the number of CAMHS beds and units available within the region. One SHA area was selected from four different NHS regions: two with a relatively high number of CAMHS beds (London and West Midlands) and two with a relatively low number of beds (Eastern and North West). Table 3.2 shows the bed provision in the four regions, together with an indicator of the level of social deprivation in each region. Further details on each area are provided in Appendix 5.0.

Table 3.2 The regions from which the SHAs, that comprise the study areas, are drawn.

NHS Region	% of SOAs[1] (rank)	CAMHS beds (units) in 2003.	CAMHS beds/ million total population in 2001
London	26.4 (4th)	309 (22 units)	43.1
West Midlands	26.3 (4th)	136 (12 units)	25.8
Eastern	6.2 (7th)	66 (6 units)	12.2
North West	32.8 (2nd)	79 (7 units)	11.7
All England	**20**	**1111 (90 units)**	**22.6**

[1]SOAs (Super Output Areas) are unit measures for indices of deprivation based on geographic areas built up from aggregating the smallest geography from the 2001 census. This column shows the percentage of SOAs in each region that fall within the most deprived 20% in England (Office of the Deputy Prime Minister, 2004). Thus, 6.2% of SOAs in the Eastern Region are among the 20% most deprived SOAs in England and the region is the seventh least deprived (of nine).

The combined total population for the four SHA areas was 7,952,273, of which 722,109 (9%) were adolescents aged 12 to 18 years (Office of National Statistics, Census 2001: Standard tables for health areas in England and Wales csv format).

3.4 RECRUITMENT OF SERVICES

Referrals could originate from a range of sources. Therefore, the research team contacted the following services by telephone and letter towards the end of 2003:

- 59 community CAMHS teams across the four SHA areas;
- GP services in the SHA areas identified from the Binley's directory and searches on trust websites;
- directors of social services in the SHA areas;
- all inpatient CAMHS units in England. Particular attention was given to:
- CAMHS units within the study SHA area in each selected region;

- independent sector services within and outside the region;
- nationally commissioned beds, such as forensic inpatient CAMHS.

During the first half of 2004 the research team visited key services within the study SHA areas to discuss the aims of the study and what the data collection would involve.

3.5 COMPONENT 1: IDENTIFICATION AND DESCRIPTION OF REFERRALS

3.5.1 Sample

3.5.1.1 Sample size

An estimate, based on the NICAPS data on referrals, assessments and admissions, indicated that, over the six-month recruitment phase, there would have been between 250 and 350 referral episodes involving young people who reside in these four areas. This would have resulted in between 160 and 220 young people being assessed and between 90 and 125 admitted.

We define a referral episode as a discrete period of time during which a referrer is seeking admission. A young person might have been subject to more than one referral episode during the six month study recruitment period. For example he/she might have been referred and admitted to one unit, discharged a month later and then referred again for admission. Furthermore, during a referral episode, a referrer might seek admission from more than one unit. For example, the first unit to which the young person was referred might have had no bed and the referrer might have sought admission elsewhere.

3.5.1.2 Inclusion criteria

Data were collected for all those who met the following criteria:

- aged between 12 and 18 years at the time of referral;
- postcode originated from within any of the four named SHA areas;
- referred between 1st November 2004 and the 30th April 2005 for an assessment for admission to an inpatient CAMHS unit.

Cases were not included if the purpose of the referral was solely for consultation or second opinion

3.5.2 Referral identification

Referrals were identified from two main sources:
- professionals from the community CAMHS teams in each SHA who were asked to report referrals by completing a 'CIRS Referral ID Form', which contained the 'CIRS minimum dataset' described under 3.2.2 (see also Appendix A 3.0);

- staff of inpatient CAMHS units, who either completed a 'CIRS Referral ID Form' or maintained an Excel spreadsheet containing the same data items. The latter proved to be the preferred option for collecting these data.

Because it was anticipated that the majority of referrals would be to units within the region in which the SHA was located, all regional units were asked to report regularly on referrals. Follow-up calls were made to collect this information throughout the six-month recruitment period and for some months after.

We identified those units outside of the SHA areas that were most likely to receive occasional referrals from our catchment population and sent them (via email) lists of the trusts and referrers in each SHA area. Units outside the regions that were thought unlikely to receive referrals from the SHA areas, were notified about the study and asked to report on whether they received any relevant referrals both during and at the end of the referral identification period.

3.5.3 Recruitment of participants

Referring clinicians were provided with a list of the referrals they made during the study recruitment period (1 November 2004 to 30th of April 2005) together with the 'CIRS minimum dataset' for each referral. A named individual at each unit to which referrals had been made (which was often the person who helped collate the CIRS referral data) was asked to liaise with the referrer to help them identify the young person concerned.

3.5.4 The CIRS Questionnaire

The 17-page questionnaire comprised mainly closed questions and incorporated two standardised scales and one adapted scale (see Appendix A 3.0). The data items were selected to address the research questions and to allow for comparisons with data from previous and current CAMHS studies such as NICAPS, CHYPIE and the Cost, Outcomes and Satisfaction for Child and Adolescent Psychiatric Services (COSI-CAPS) study.

Section 1: Demographic variables
Section 2: Referral details: questions on the reasons for admission and non-admission, and on factors that influenced the clinician's decision to refer.
Section 3: Mental Health Act / Children Act status
Section 4: Service-use history six months prior to and post, the 'index' referral
Section 5: Diagnosis (categories based on the ICD-10 Classification of Mental and Behavioural Disorders)
Section 6: Psychosocial complexity: questions were adapted from the Paddington Complexity Scale (Yates, Garralda, and Higginson, 1999)
Section 7: Clinical severity ratings:
  i)   Children's Global Assessment Scale (Shaffer et al., 1983); with an option to indicate whether the score was recorded close to the time of referral or whether it was based on the clinician's memory of the young person's functioning at the time of referral;

ii) Health of the Nation Outcome Scales for Children and Adolescents (Gowers et al., 1999) if recorded close to the time of referral.

3.5.5 Procedure for collecting data

We posted a study questionnaire, with a letter and a freepost envelope, to referring clinicians for each young person referred. Each questionnaire was coded and contained the CIRS minimum dataset to help the referrer identify the young person. Clinicians who did not return the questionnaire were contacted and invited to complete it via a structured telephone interview with the researcher. If the referring clinician was unable to recall the identity of the young person, they were asked to contact the 'study link' person in the relevant inpatient unit for this information prior to the telephone interview. The referring clinician had access to the young person's case notes during the telephone interview with the researcher. When the researcher collected the data by telephone interview, she adhered to the exact phrasing of each question and response option.

3.5.6 Data analysis

Descriptive statistics were employed to describe:
- the number and pattern of referrals that emerged from the four SHA population bases;
- the spread of referrals made to different units (general or specialist; NHS or Independent sector) within and outside the region.

Descriptive statistics and tests of significance were employed to:
- compare the characteristics of those admitted with those referred but *not* admitted population.

3.5.7 Impact of problems with research governance and ethics approvals

Due to the delays and problems described above, the research team focused on identifying all referrals arising from two of the four SHA areas, the SHA in the London Region, which is largely an urban area, and that in the Eastern Region, which is largely a rural area.

3.6 COMPONENT 2: STRUCTURED TELEPHONE INTERVIEWS WITH PROFESSIONALS TO TRACK THE CARE PATHS OF THOSE NOT ADMITTED

3.6.1 Design

This component described the subsequent care paths of those young people who had been referred for inpatient care between 1st November 2004 and the 30th April 2005 but had not been admitted. The information, which covered a two year period following the referral, was collected retrospectively. Data were collected on referrals that emerged from two of the four SHA areas (one in London and one in the East).

3.6.2 Sample

3.6.2.1 Size

Based on the NICAPS figures described under 3.5.1.1, the sample size was estimated to be about 150 cases.

3.6.2.2. Inclusion criteria

Data were collected on the care paths of those who were not admitted to the first unit to which they had been referred irrespective of the reasons for non-admission. This group included some young people who were referred on, and subsequently admitted, to another unit during the "referral episode".

3.6.3 The Interview Schedule

The structured interview schedule used in Component 2 builds on data received from the CIRS questionnaire for each young person and contains five pages of closed and open questions in the following sections (Appendix A 3.0):

Section 1: Open and closed questions on the young person's service history and contact with the professional being interviewed. The names and contact details for other relevant professionals were sought.

Section 2: Questions to obtain the clinicians' views on the appropriateness of the care provided.

Section 3: Young person's and parent or carer's engagement with care and treatment offered. This included an adapted version of MARC 2 - a standardized tool employed to assess the service needs of adults with mental health problems (Huxley et al., 2000).

Section 4: Three questions from the Paddington Complexity Scale on the young person's current circumstances in relation to their accommodation, main carer, education status, and risk.

Section 5: Other details thought to be relevant by the clinician.

3.6.4 Procedure for collecting data

The researchers undertook structured telephone interviews with the key clinician(s) that provided care to the young person during the 24 month period following the index referral. This initial contact was with the same clinician who had first referred the young person to an IP CAMHS unit and who had completed the CIRS questionnaire.

3.6.5 Data analysis

The free text responses to open questions and the responses to closed questions were reviewed by the main researcher to identify different types of care pathways. These data were combined with referral and service contact data from the main CIRS questionnaire to construct a detailed account of the care path followed by each young person. These accounts were compared and contrasted to create a typology of the care paths followed by those not admitted when first referred (discussed further in 4.3.2).

3.7 COMPONENT 3: QUALITATIVE INTERVIEWS WITH THOSE NOT ADMITTED

This component of the study could not be completed. Young people were invited to participate through the professional they were last in contact with and were selected according to the type of care path they had followed. The aim was to interview young people in order to capture a range of care path experiences. Enquiries were made about inviting a total of 41 young people. Nineteen of these were viewed to be not appropriate or were no longer in contact with the service, one young person and their parents actively declined. The remaining 21 young people were invited through the professional they last had contact with. Of those who were sent a consent pack, six returned their form consenting to an interview but only four agreed to arrangements to meet with the researcher for an interview. Due to the low response it was not possible to complete this component of the study and it is not reported further here.

3.8 COMPONENT 4: DEVELOPMENT OF CRITERIA TO DEFINE THE FACTORS THAT CONSTITUTE 'APPROPRIATENESS' FOR ADMISSION

3.8.1 Design

This sub-study had three stages: i. literature review; ii. group interview with CAMHS professionals on admission criteria; iii. modified two-round Delphi consultation questionnaire survey to achieve consensus among referring and admitting professionals.

3.8.2 Stage 1: Literature review

The purpose was to identify criteria that have been reported to be determinants for admission to adolescent mental health services. The databases that were searched were medline (1986-2006;), psychinfo (1985-2006) and embase (1980-2006). The search terms included: 'admission' AND 'determinants or criteria' AND 'child$ or adole$', followed by a further search under 'psychiatric' or 'mental health' or 'CAMHS' and 'inpatient'. The abstracts of papers identified were read to determine which articles were relevant and reference lists were searched (see Appendix A 1.5 table A 1.4 for papers).

3.8.3 Stage 2: Group interview

The purpose of the group interview was to a) elicit clinicians' views on the factors that influence their decisions to refer and admit to in-patient CAMHS units and b) explore what constitutes 'appropriateness' for admission (see Appendix A 3.0 for group interview guide). The overall aim was to confirm that the factors reported in the literature were relevant to practicing clinicians and to see if any other issues arose.

An advert was placed on the FOCUS mailbase, which is a resource for CAMHS professionals to hold email discussions on issues relating to CAMHS. Ten professionals replied and from this group eight professionals representing

different types of CAMHS provision were selected. On the day of the interview five CAMHS professionals participated: one NHS community-based CAMHS psychiatrist; one NHS inpatient CAMHS psychiatrist who had previously worked for many years in community CAMHS team; one Independent sector inpatient CAMHS psychiatrist, one nurse consultant who managed an adolescent in-patient unit, and one CAMHS commissioner.

The interview was recorded and transcribed verbatim. Two researchers independently reviewed the interview transcript and identified the emerging themes. The themes identified by both researchers were compared and a final set of themes were agreed and identified.

3.8.4 Stage 3: Modified two-round Delphi consultation survey

A modified two-round Delphi technique was employed to attempt to achieve consensus among inpatient and community CAMHS professionals. In accordance with the Delphi technique, the individual ratings were kept confidential and a participant's individual scores and the group scores for each item were fed-back to inform their second rating. The process was supported by the multi-professional CIRS advisory group which met twice times to discuss the emerging findings from this component.

3.8.4.1 First rating

Following the literature review and group discussion, we created a questionnaire that incorporated the factors that might influence the decision to admit a young person to an inpatient unit. The CIRS Admission Questionnaire (Appendix A 3.0) had two sections. Section 1 comprised four closed questions that asked participants to state whether they would admit or request an admission to a general purpose or specialist eating disorder unit for an adolescent who they thought did not have a severe mental illness but who presented with a) challenging behaviours or conduct disorder; b) a substance misuse problem; c) a developmental disorder; d) a learning disability. The second section comprised a list of 17 possible indications for admission that were derived from the literature review and the group interview. In this section, participants were asked to assume that a young person does have a severe mental illness (SMI) and to rate how important each criterion was to their clinical decisions to refer or admit a young person with an SMI to general purpose or eating disorder inpatient CAMHS adolescent unit. The scale ranged from 1=not at all important to 5=of major importance and 6= main determinant in combination with severe mental illness. The criteria were randomised to produce 10 randomised versions of the questionnaire to avoid order effect.

In April 2006, the questionnaire was sent to two groups of CAMHS professionals. The first group was 182 professionals (mainly psychiatrists and senior nurses or nurse managers) working in all adolescent IP CAMHS in England. These individuals were identified through a database the research team had maintained from the NICAP study and the Quality Network for Inpatient CAMHS (QNIC). The second group was the 203 community CAMHS professionals (nurses, psychiatrists, social workers, clinical psychologists) who worked in the four study SHA areas and who had been identified as potential referrers of young people for inpatient care. We sent the questionnaire for a second time to non-responders in May 2006.

We created a table of the results showing the mean rating given to each potential admission criterion by all survey respondents.

3.4.8.2 Second rating

In September 2006, we sent a second survey questionnaire to each professional who had responded to the first survey, together with a summary of that person's own rating for each item and the mean rating for each item by all raters. A reminder was sent to non-respondents one month later.

3.8.4.3 Data analysis

Basic descriptive statistics were applied to describe the frequency of participants who rated the item as important or very important to their decision to refer or admit to an inpatient CAMHS unit. A kappa coefficient was used to assess the intra-rater agreement between the two surveys in admission criteria. Kappa value of greater than 0.4 was considered as a good agreement between the two surveys.

4. RESULTS

4.1 INTRODUCTION

Due to the problems encountered in gaining ethics and research governance approvals, we present results about referrals arising from two SHA areas (one in the Eastern Region and one in the London Region). Appendix A 5.0 describes the CAMH services available in these areas during the study period. Table 3.2 in Chapter 3 shows the number of CAMHS beds located within the Eastern and London Regions.

Note: Our main unit of analysis is the "referral episode" which we define as a discrete period of time during which a referrer is seeking admission. A young person might have been subject to more than one referral episode during the six month study recruitment period. For example he/she might have been referred to and admitted to one unit, discharged a month later and then referred again for admission. Furthermore, during a referral episode, a referrer might seek admission from more than one unit. For example, the first unit to which the young person was referred might have had no bed and the referrer might have sought admission elsewhere.

4.2 COMPONENT 1: DESCRIPTION OF REFERRALS

4.2.1 Referrals to inpatient CAMHS units from two SHA population bases.

During the study period there were 159 referral episodes concerning a total of 143 young people (16 young people were referred on two separate occasions). Table 4.1 shows the rate of referral episodes standardised for the age-specific populations of the two SHA areas and the demographic characteristics of the young people who were the subject of the 159 referral episodes.

When standardised for population size, there were more than twice as many referral episodes during the six months in the London SHA than in the East SHA (90 vs 39 per 100,000 population aged 12-18). The rate of referral in London was significantly higher than in the East both for males ($z=4.95$; $p<0.001$) and for females ($z=3.46$; $p<0.001$).

There was no difference between the two areas in the mean age of the young people who were the subject of referral episodes ($t=1.80$; df $=156$; $p=0.07$). However, the age profile did differ (figure 4.1). The group referred in London contained a significantly higher proportion of both younger children, age 12-13 ($z=2.99$; $p<0.01$), and older adolescents, age 16-17 ($z=4.81$; $p<0.001$), than did the East SHA area.

Table 4.1 Description of the young people referred to IP CAMHS arising from two SHA areas

	East SHA n (%)	London SHA n (%)	Combined n (%)
Population			
Total	2,174,015	1,178,437	3,352,452
12 to 18 year olds (% of total)	185,591 (8.5)	95,633 (8.1)	281,224 (8.4)
Referrals			
Number of referral episodes[1]	73	86	159
Referral episodes/100,000 12-18 yrs	39	90	57
Basic demographics			
Gender			
Male	13 (18)	30 (35)	43 (27)
Female	56 (77)	55 (64)	111 (70)
Missing	4 (5)	1 (1)	5 (3)
Gender (Referrals per 100,000 population of 12-18 yrs old)			
Male	7	31	15
Female	30	58	40
Age[2]			
Mean age	14.9 (sd 1.2)	15.3 (sd 1.5)	15.1 (sd 1.4)
12 – 13	7 (10)	13 (15)	20 (13)
14 – 15	41 (57)	30 (35)	71 (45)
16 – 17	24 (33)	41 (48)	65 (41)
18	0	2 (2)	2 (1)

[1] 16 young people were subject to two referral episodes during the study period.
[2] Age missing for 1 case.

Figure 4.1 Referrals per 100,000 age specific population (12 to 18 years) in the London SHA and the East SHA.
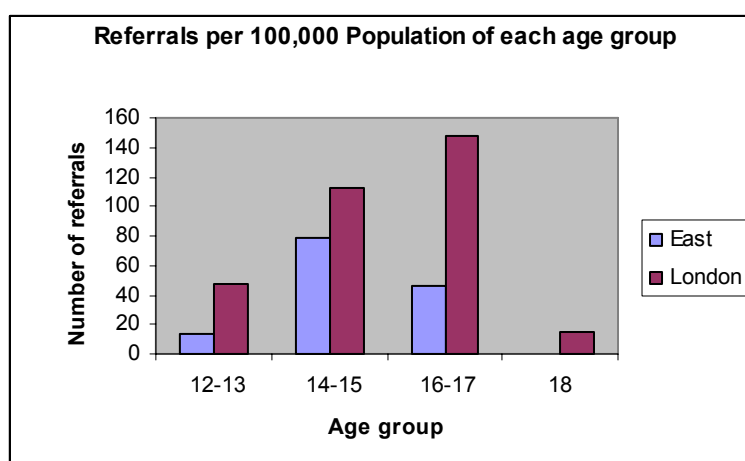
4.2.1.1 Overall Pattern and outcome of referral episodes

During the referral episode, 121 young people were referred to a single unit, 31 were referred to two units and 7 to three or more units. Figure 4.2 shows the pattern and outcome of referrals for the 159 referral episodes.

Figure 4.2 Pattern and outcome of the 159 referral episodes

159 referrals to first unit—91 not admitted—65 admitted—3 outcome unknown

↓

38 referred to second unit—9 not admitted—29 admitted

↓

7 referred to third unit—3 not admitted—4 admitted

↓

2 referred to fourth unit—2 admitted
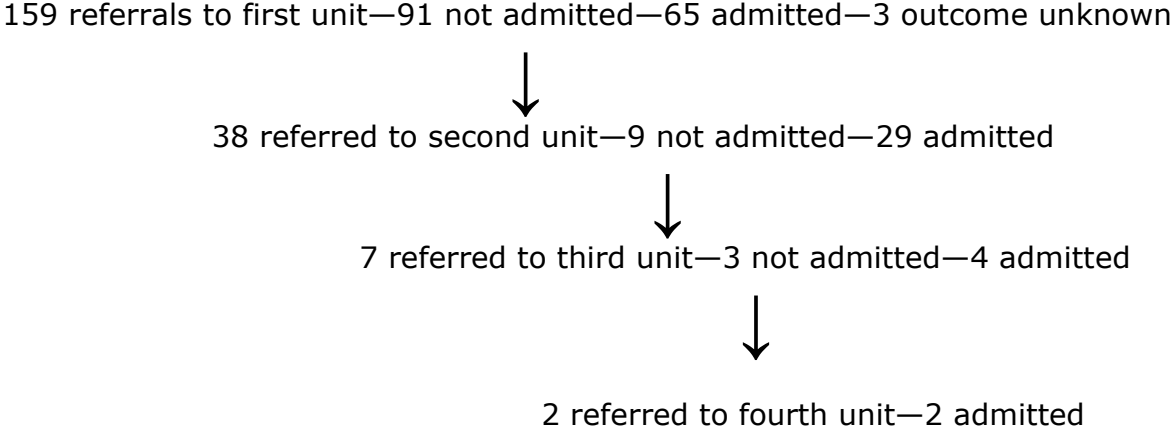
As can be seen, 38 of the 91 young people who were not admitted to the first unit to which they had been referred, were referred on to other units during the same referral episode. These young people were subject to a total of 47 subsequent referrals (31 were referred to two CAMHS units, seven to three units and two to four units).

The referral episode resulted in admission for 100 young people (63% of the total). Sixty five of these (41% of the total) were admitted to the first unit to which they had been referred. Fifty three of the 91 young people (58%) for whom the referral episode did not result in an admission, were only referred to one unit. That is, the first referral resulted in the decision that the young person would not be admitted.

Figures 4.3 and 4.4 shows the pattern and outcome of referrals for the two SHA areas separately.

Figure 4.3 Pattern and outcome of the 86 referral episodes in the London SHA

86 referrals to first unit—46 not admitted—38 admitted—2 outcome unknown

↓

20 referred to second unit—5 not admitted—15 admitted

↓

3 referred to third unit—1 not admitted—2 admitted

↓

None were referred to a fourth unit
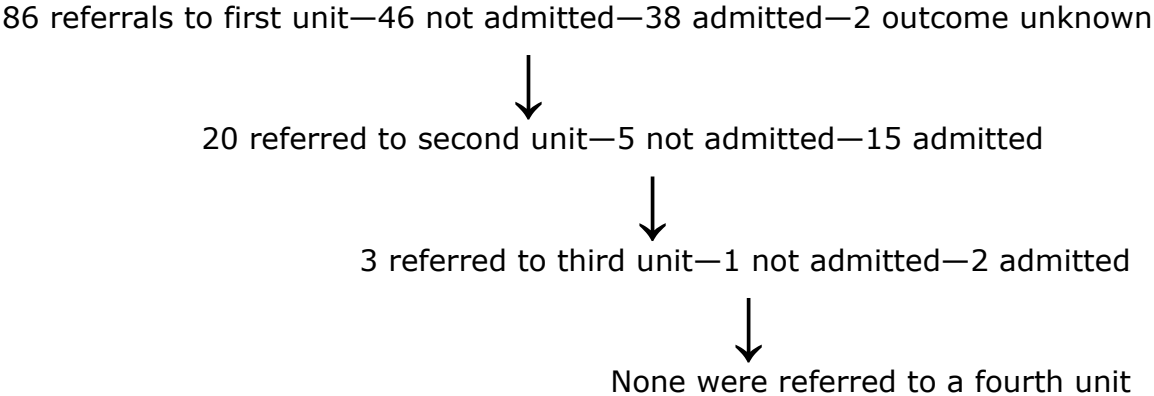
Figure 4.4 Pattern and outcome of the 73 referral episodes in the East SHA

73 referrals to first unit—45 not admitted—27 admitted—1 outcome unknown

↓

18 referred to second unit—4 not admitted—14 admitted

↓

4 referred to third unit—2 not admitted—2 admitted

↓

2 referred to fourth unit—2 admitted
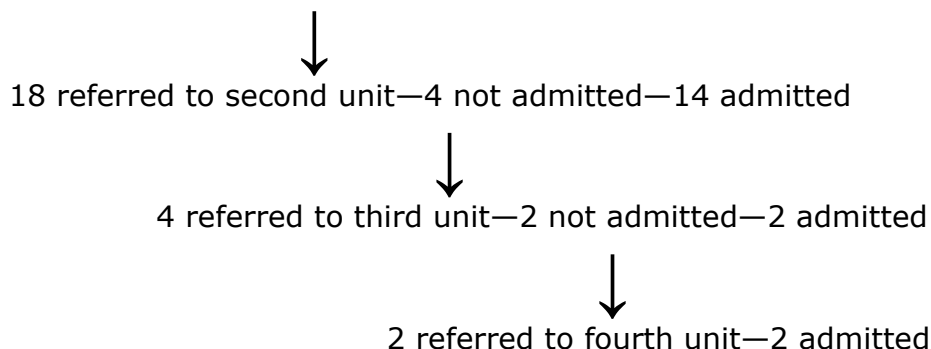
There were no significant differences between the SHAs for:

- the proportion of young people who were subsequently referred on to another unit after not being admitted to the first (23% in London compared with 25% in the East);
- the proportion admitted to the <u>first</u> unit referred to (44% in London compared with 37% in the East);
- the proportion admitted to any unit during the study period (64% in London compared with 62% in the East);
- the proportion <u>not</u> admitted to any unit (34% in London compared with 37% in the East).

4.2.2 Destination of referrals

In both areas the commonest pattern was for the first referral to be to an NHS unit within the region, followed by an onward referral to an independent sector unit. In keeping with this, a higher proportion of subsequent referrals were to the independent sector than was the case for the first referrals (22% [35 of 159] of first referrals compared with 81% [38 of 47] of subsequent referrals; z = 7.65; p<0.01).

Taking all 206 referrals into account (159 first referrals and 47 subsequent referrals), a higher proportion of referrals to independent sector units resulted in an admission than did those to the NHS (62 of 73 vs 38 of 133; z= 7.42, p<0.001).

4.2.2.1 Destination of first referrals

Table 4.2 shows the destination of first referrals for the 159 referral episodes for the whole cohort and separately for the two SHA areas. A higher proportion of first referrals that were to the independent sector resulted in an admission than was the case for first referrals that were to an NHS unit (89% of first referrals that were to the independent sector compared with 27% of first referrals that were to the NHS; z=6.30; p<0.001).

Table 4.2 Destination of first referrals (total n=159) and the number that resulted in admission to that unit.

	Number of first referrals (number that resulted in admission)					
	East SHA		London SHA		Combined	
	Within region	Outside region	Within region	Outside region	Within region	Outside region
NHS[1]						
General adolescent unit	33 (6)	2 (0)	28 (6)	0	61 (12)	2 (0)
General adolescent-acute unit	0	0	38 (15)	0	38 (15)	0
General children's unit	0	0	0	0	0	0
Eating disorder unit	23 (7)	0	0	0	23 (7)	0
Total NHS	56 (13)	2 (0)	66 (21)	0	122 (34)	2 (0)
Independent sector[1]						
General adolescent unit	10 (10)	5 (4)	18 (15)	1 (1)	28 (25)	6 (5)
Eating disorder unit	0	0	1 (1)	0	1 (1)	0
Total independent	10 (10)	5 (4)	19 (16)	1 (1)	29 (26)	6 (5)
Total[1]						
NHS and independent	66 (23)	7 (4)	85 (37)	1 (1)	151 (60)	8 (5)

[1] See Appendix A 1.0, table A 1.3a for definitions of different types of CAMHS units

4.2.2.2 Destination of subsequent referrals

Table 4.3 shows the destination and outcome of the 47 subsequent referrals.

Table 4.3 Types of unit to which subsequent referrals were made (total n=47) and the number that resulted in admission to that unit.

	Number of first referrals (number that resulted in admission)					
	East SHA		London SHA		Combined	
	Within region	Outside region	Within region	Outside region	Within Region	Outside region
NHS						
General adolescent unit	2 (2)	1	3 (1)	0	5 (3)	1
General adolescent-acute unit	0	0	1	0	1	0
General children's unit	0	0	2 (1)	0	2 (1)	0
Eating disorder unit	0	0	0	0	0	0
Total NHS	2 (2)	1 (0)	6 (2)	0	8 (4)	1 (0)
Independent sector						
General adolescent unit	12 (8)	9 (7)	17 (16)	0	29 (24)	9 (7)
Eating disorder unit	0	0	0	0	0	0
Total independent	12 (8)	9 (7)	17 (16)	0	29 (24)	9 (7)
Total						
NHS and independent	14 (10)	10 (7)	23 (18)	0	37 (28)	10 (7)

Tables 4.2 and 4.3 show that of the 100 referral episodes that resulted in admission: i. 38 admissions were to an NHS unit and 62 were to an independent sector unit and ii. 88 admissions were to a unit within the region and 12 were to a unit outside of the region.

There were no differences between the two areas in:

- the proportion of referral episodes that involved a referral to more than one unit (25% in the East compared with 23% in London);
- the proportion of first referrals that were to an NHS unit (78% in the East compared with 79% in London); or,
- the proportion of NHS first referrals that resulted in an admission (22% in the East compared with 32% in London; $z=1.71$; $p > 0.05$);
- the proportion of young people whose admission was to an independent sector unit (66% in the East compared with 59% in London).

However, compared with London, referral episodes in the East were more likely to include at least one referral to a unit outside of the region (17 of 73 in the East compared with 1 of 86 in London). In London, only one of the 56 young people who were admitted during the referral episode was admitted to a unit

outside of the London Region. In contrast, in the East 11 of the 44 young people who were admitted during the referral episode were admitted to a unit outside of the Eastern Region.

4.2.2.3.1 Types of unit to which the young people were referred

Overall, 179 of the 206 first and subsequent referrals (67%) were to a general adolescent unit provided by either the NHS (n=107; 52% of all first and subsequent referrals) or the independent sector (n=72; 35% of all first and subsequent referrals). The most striking difference between the two areas was that a higher proportion of all referrals in the East were to a specialist eating disorder unit located in the region (23 referrals in the East – resulting in seven admissions – compared with one referral and one admission in London).

4.2.2.3.2 Transfers to other units during an admission

Eight young people who were referred and admitted during the study period had their care transferred to another unit during their inpatient stay. In London, six young people were transferred from an independent sector general adolescent unit to a similar type of unit managed by the NHS and one young person was transferred from one independent general adolescent unit to another. In the East SHA one young person was transferred to an independent sector medium secure CAMHS unit outside the region.

4.2.3 The characteristics of those admitted and those not admitted

The clinicians involved in each young person's care, often the referrer, provided questionnaire data for 105 of the 159 (66%) referral episodes. Data were collected for 53 of the 73 (73%) referral episodes from the East SHA and 52 of the 86 (61%) from the London SHA. The referral episodes resulted in an admission for 67 of these 105 young people (64%). Of these, 36 were admitted to the first unit they were referred to and 31 to the second, third or fourth unit that they were referred to. Table 4.4 below compares the 105 young people for whom questionnaires were completed with the 54 for whom they were not.

Table.4.4 Comparison between the 105 young people for whom questionnaires were completed with the 54 for whom they were not

	With questionnaire (n=105) N (%)	Without questionnaire (n=54) N (%)	All (n=159) N (%)
Gender			
Male (%)-5 missing	29 (28%)	14 (26%)	43 (27%)
Age			
Mean age (sd)-1missing	15 (1.3)	15.4 (1.5)	15.1 (1.4)
Age 12 – 13 (%)	15 (14)	5 (9)	20 (13)
Age 14 – 15	50 (48)	22 (41)	72 (45)
Age 16 – 17	40 (38)	24 (44)	64 (40)
Age 18	0	2	2
Number of units referred to			
One unit	71 (68)	50 (93)	121 (76)
More than one unit	34 (32)	4 (7)	38 (24)
Number of admitted to			
First unit	35 (33)	30 (56)	65 (41)
Another unit after first referral	32 (30)	4 (7)	36 (23)
Referral outcome unknown	0	3	3

Those for whom questionnaire data were collected closely resembled the whole cohort in terms of age and gender. The group with questionnaire data contain a higher proportion of young people who had more than one referral during their referral episode. Some of this difference might be accounted for by us having collected incomplete information about pathways subsequent to first referral for those young people for whom we were unable to interview a care professional.

4.2.3.1 Comparison of the characteristics of those admitted with those not admitted

Table 4.5 compares the 65 young people who were admitted during the referral episode with the 38 that were not admitted – for the sample with complete data. Where numbers allowed tests of significance were undertaken. We undertook a logistic regression analysis to determine which factors significantly predicted an admission to IP CAMHS. The number of variables we would include in the equation was limited by the small sample size. The variables included were: age, level of risk, self-harm, suicidal attempt, CGAS score and diagnosis. Only suicidal attempt proved a significant predictor for admission (odds ratio: 12.9; $p < 0.05$). Young people who have attempted suicide are 13 times more likely to be admitted than those who have not.

Nineteen of the 65 young people who were admitted were admitted under a section of the Mental Health Act: section 2 – admission for assessment applied to12 young people, section 3 – admission for treatment applied to five young people, and section 136 – mentally disordered persons found in public places applied to one young person. The type of act was missing for one young person.

Table 4.5 Characteristics of those admitted and those not admitted[1]

Young People's Characteristics		Number (%)		Test of significance (FE=Fisher's Exact NS=Not significant)
		Admitted (N=67)	Not admitted (N=38)	
Male		20 (30)	10 (26)	NS
Age 12-13		8 (12)	6 (16)	
Age 14-15		28 (42)	24 (63)	NS
Age 16-17		31 (46)	8 (21)	
White-British		50 (75)	35 (92)	NS
BME groups		15 (22)	3 (8)	
Accommodation at time of referral	Living in the family home	39 (58)	31 (82)	
	Foster care/children's home	5 (8)	4 (11)	
	Independently/with relatives	3 (4)	2 (5)	
	Adult psychiatric ward	5 (8)	1 (3)	
	Paediatric ward	11 (16)	0	
	Others	4 (6)	0	
Main carer	Both natural/adoptive parents	23 (34)	21 (55)	
	Single parent/natural parent & partner	32 (48)	10 (26)	
	Living with relatives	3 (4)	1 (3)	
	Foster care/children's home	8 (12)	5 (13)	
	Other (living independently)	0	1 (3)	
Source of referral	CAMHS psychiatrist	60 (90)	30 (79)	
	Other community CAMHS worker	3 (4)	2 (11)	
	General Practitioner	3 (4)	3 (8)	
	Accident and Emergency Dept.	1 (1)	0	
	Others	0	3 (8)	
Type of referral[2]	Emergency (within 24 hours)	41 (61)	7 (18)	FE; p<0.001
	Planned for assessment	12 (18)	21 (55)	FE; p< 0.001
	Planned for treatment	21 (31)	17 (45)	NS
Legal status	Children Act applied-yes	12 (18)	6 (16)	NS
	Mental Health Act applied-yes	19 (28)	0	
Diagnosis	Mood (affective) disorders	24 (36)	6 (16)	FE; p<0.001
	Eating disorders	9 (13)	13 (34)	
	Schizophrenia, delusional or psychotic disorders	10 (15)	1 (3)	
	Other diagnoses/not known	22 (33)	17 (45)	
Presence of learning disability	None	51 (76)	29 (76)	
	Specific learning difficulty	9 (13)	7 (18)	
	Generalised -mild (IQ 50 to 69)	3 (4)	1 (3)	
	Generalised but IQ not tested	1 (1)	0	
Clinical severity	CGAS score	33	41	Mann Whitney U; Z=-3.05; p<0.01
	CGAS score missing	22 (33)	11 (29)	
Risk	Risk to self	48 (72)	23 (61)	NS
	Risk to others	3 (5)	1 (3)	
	Risk to both self and others	11 (16)	3 (8)	
	Not at risk to self or others	5 (7)	10 (26)	
	Suicidal attempt ever	25 (37)	5 (13)	Chi=7.5; df=1; p<0.01
	Ever self-harmed	43 (64)	17 (45)	NS
	Presence of any abuse	27 (40)	13 (34)	NS
Education	Attending some form of education	48 (91)	41 (79)	NS
	Excluded/suspended from school	5 (10)	11 (26)	

[1] There were small numbers of missing data for some items
[2] Categories not mutually exclusive, therefore figures for missing information not provided.

Of the 48 young people referred for an emergency admission, seven were not admitted to any unit and 41 were admitted. Of those admitted, half (n=20) were admitted to the first unit they were referred to and the other half (n=21) had to be referred on to another unit after being denied access to the first. Eighteen of the 20 admitted to the first unit (90%) were admitted within 24 hours or the next working day, whereas only 12 of the 21 (57%) referred on to another unit were admitted during this time frame. For the remaining nine young people from this group, six were admitted two or three days after the referral, two were admitted 4 or 5 days later and one was admitted after more than a week after the first referral. Twenty of the 21 (95%) referred on to another unit were admitted to an independent sector unit after not being admitted to an NHS unit (10 in the East and 10 in the London SHA area). Five of these were transferred back to an NHS unit at a later date.

4.2.3.2 Factors that influenced the decision to refer for admission.

The factor that was most often reported as the primary reason for the referral was risk to self or others (ranked first for 80 out of 105 young people). Also, it was the second reason why a further 13 young people were referred. Other factors considered important (ranked as the first, second or third reason for referral) for a substantial number of young people were:
- the young person was not responding to treatment provided on an out-patient basis (n=38);
- the need to provide a detailed psychiatric assessment in a controlled environment (n=22);
- the ability of the family to cope (n=18).

Other factors less frequently reported (ranked as the first, second or third reason) were:
- to improve control over the young person's behaviour (n=6);
- to establish better therapeutic control (n=6);
- to facilitate future placements (n=5);
- to achieve psychological separation between the parents and the young person (n=3);
- to provide therapeutic peer-group experience (n=2).

The lack of available services was given lower priority (ranked from the 4th to 10th reason) for 7 cases.

4.2.3.3 Reasons why young people were not admitted

We consider two groups of young people who were referred but not admitted; those who were not admitted to any unit during the referral episode (n=38) and those who were not admitted to the first unit to which they had been referred but who were referred on and subsequently admitted to another unit (n=31).

For those not admitted to any unit, the main reasons for non-admission were:
- the young person or parent refused an offer of a place (n = 22);
- unit staff considered that the young person did not need IP CAMHS care (n=9);
- the condition of the young person improved after an assessment or while they were waiting for an assessment or admission (n=5);
- the young person's very low weight necessitated admission to a paediatric ward (n=2).

For the 31 young people who were not admitted to the first unit, but were referred on and subsequently admitted to another, the reasons for not being admitted to the first unit to which they had been referred were:

- no bed was available (n=22);
- the young person or their relatives refused admission (n=4);
- the young person was approaching the age limit of the unit (n=1);
- the unit could not offer admission soon enough (n=1).
- Data were missing for three cases.

There was a secondary reason for the non-admission of five young people: the unit was unable to contain risk to others (n=1); no evidence of a mental disorder (n=1); young person's age was outside the unit's age-range (n=1); no available beds (n=1); young person lives outside the admission boundaries of the unit (n=1).

4.2.3.4 Young people's contact with services before and after referral

The young people referred for admission made heavy use of services both during the six months before referral and during the six months after referral. This was true whether they were admitted as a result of the referral or not. Table 4.6 shows the number of young people who had contact with various health and social care services and professionals.

Table 4.6 Type of services and professionals that young people were in contact with six-months pre- and post-referral by admission status

Types of services/professionals contacted	Admitted N=67 (%)		Not admitted N=38 (%)	
	Pre-referral	Post-referral	Pre-referral	Post-referral
1 A&E or adult general medical ward	26 (38)	10 (15)	8 (21)	2 (5)
2 In-patient CAMHS unit	13 (19)	67 (100)	3 (8)	8 (21)
3 Day-patient CAMHS	2 (3)	1 (1)	0	5 (13)
4 Paediatric ward	21 (31)	4 (6)	8 (21)	4 (11)
5 Adult mental health ward	9 (13)	6 (9)	1 (3)	2 (5)
6 Community CAMHS	54 (81)	58 (87)	30 (79)	35 (92)
7 Community CAMHS psychiatrist	40 (60)	44 (66)	26 (68)	28 (74)
8 CAMHS CPN, outreach worker, primary mental health worker	15 (22)	29 (43)	11 (29)	14 (37)
9 Family or individual therapist (incl. art or occupational)	34 (51)	36 (54)	25 (66)	28 (74)
10 Clinical psychologist	10 (15)	9 (13)	10 (26)	12 (32)
11 Paediatrician (outpatient)	2 (3)	2 (3)	1 (3)	1 (3)
12 Adult mental health teams	2 (3)	7 (10)	0	2 (5)
13 General practitioner	2 (3)	9 (13)	0	5 (13)
14 Dietician	1 (1)	0	3 (8)	3 (8)
15 Social worker	27 (40)	29 (43)	12 (32)	13 (34)
16 Children's home	4 (6)	2 (3)	2 (5)	1 (3)
17 Connexions	9 (13)	7 (10)	2 (5)	4 (10)
18 Educational services (welfare officer/psychologist, special educational needs co-ordinator)	7 (10)	8 (12)	13 (34)	8 (21)

Before referral, 84 of the 105 young people (80%) had had contact with community CAMHS; 66 of these (79%) had seen a community CAMHS psychiatrist. Thirty three (31%) had attended an emergency department and/or

been admitted to a general medical ward. Thirty nine (37%) had had contact with a social worker. The general pattern was for young people to have had contact with multiple different agencies or professionals before referral – a mean of three (range 0-8 different services/ professionals).

There was no significant difference between those admitted and those not admitted, as a result of the referral episode, in the number of services (mean of three) that young people had contact with either before (Mann Whitney U Test: z=1.28; p=0.20) or after referral (Mann Whitney U Test: z=1.63; p=0.10). There was also no significant difference found for the number of professionals (mean of four) they were in contact with either before (Mann Whitney U Test: z=1.31; p=0.19) or after the referral (Mann Whitney U Test: z=1.22; p=0.22).

4.2.3.4.1 Those admitted to an adult mental health ward

Seventeen, of the 105 young people for whom we have care path data, were admitted to an adult mental health ward at some point in the six months before or six months after the referral episode (one young person was admitted both before and after their referral episode). This group comprised: one female aged 13, one female aged 15, eight females and three males aged 16, and two females and two males aged 17 years. Two of the 16 year olds (one male and one female) and one of the 17 year old males were not admitted to any IP CAMHS unit during the study period. The primary diagnoses of these 17 young people who had admissions to adult wards were: mood (affective) disorder (n=6); neurotic, stress-related, and somatoform disorders (n=5); schizophrenia, delusional or psychotic disorders (n=2); mental disorder due to psychoactive substance misuse (n=1); personality disorder (n=1) and eating disorder (n=1). The diagnosis was unknown for one young person. Eight (47%) of these young people were admitted following a suicide attempt.

Nine of the 17 young people were referred and admitted to a CAMHS unit after having been admitted to an adult ward. Six of these had been referred to the CAMHS unit, as an emergency, directly from the adult mental health ward with the support of a community CAMHS team. The other three had been discharged to the care of the community CAMHS team before being referred on to IP CAMHS for a planned assessment (for one case) or planned treatment (for two cases).

Nine young people were admitted to an adult mental health ward at some point in the six-months <u>after</u> their referral episode (one young person had been admitted to an adult ward both before and after the referral episode). For six of these young people, the referral episode had resulted in admission to a CAMHS unit before. For all six, the admission to an adult ward had occurred some time after they had been discharged from the CAMHS unit; that is, none were admitted to an adult ward directly from a CAMHS unit. The other three young people, who were admitted to an adult ward after the referral episode, were not admitted to any CAMHS unit at all. We describe two of these young people in more detail below.

- **Young person 1** was a female aged 16 who was being accommodated by social services outside her home area. She first presented at an accident and emergency department and was assessed by the adult mental health emergency assessment centre based at the hospital. The diagnosis was unknown. The assessment team made an emergency referral to the local NHS CAMHS unit. The young person was denied a bed because she lived outside of the catchment area for that unit. She was subsequently admitted to an adult

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psychiatric ward for two days while the assessment team referred her to a local community CAMHS team and arranged for her to receive intensive community care by a crisis resolution team for six weeks. After this period of intensive care the young person did not engage well with the community CAMHS team to which she was referred, dropping in and out of contact. The young person later moved back to her home area and the community CAMHS team discharged her care to another community CAMHS team near to her home with whom she had had prior contact before the referral episode.

- **Young person 2** was a female aged 17 was referred, assessed and placed on the waiting list for a bed in a CAMHS eating disorders unit, but while waiting for a bed her condition improved and she no longer required a bed. She continued with community CAMHS treatment and as she approached her 18th birthday her care was transferred to an adult specialist eating disorder community team. Shortly after the transfer this young person required an admission to an adult eating disorder unit where she received treatment for a number of months. After discharge the young person was reported to be engaged with the adult community team and was doing well.

4.2.3.4.2 Admissions to paediatric wards

Thirty-two young people were admitted to a paediatric ward at some point in the six months before or six months after the referral episode. Eleven (34%) of these young people were admitted after a suicide attempt. Five young people were admitted both before and after their referral episode. The primary diagnosis for each of these 32 young people was: eating disorder (n=10); mood (affective) disorder (n=11); mental and behavioural disorder due to psychoactive substance misuse (n=3); a neurotic, stress-related somatoform disorder (n=3); schizophrenia, delusional or psychotic disorders (n=1); disorder of adult personality and behaviour (n=2); diagnosis was missing for two young people. The age and gender of these 32 young people was: four females and one male aged 13 years; nine females and one male aged 14 years; six females and one male aged 15 years; three females and four males aged 16 years; one female was aged 17 years. Age was missing for two cases.

Four of the 32 young people were admitted to a paediatric ward after having been referred but not admitted to any IP CAMHS unit. Three of these young people had a primary diagnosis of an eating disorder and one had a diagnosis of a neurotic, stress-related and somatoform disorder. The circumstances of these four admissions to a paediatric unit were:

- **Young person 1** was assessed and placed on a waiting list but required admission to a paediatric ward due to severe loss of weight. While on the paediatric ward, this young person's weight improved and it was decided that she could continue with outpatient CAMHS treatment.

- **Young person 2** was assessed and offered a place on the IP CAMHS unit but this was declined by the young person or her parents. The young person continued to lose weight and later required an emergency admission to a paediatric ward. This was later followed by a re-referral and admission to the CAMHS eating disorder unit where she received treatment for a period of five months.

- **Young person 3** was admitted to a paediatric ward, both before and after the referral episode, for medical treatment caused by extremely low weight. The referring clinician reported that on both occasions her weight was too low for an admission to a CAMHS unit.

- **Young person 4** was a 14 year old female who had a diagnosis for a neurotic, stress-related and somatoform disorder and was not admitted to IP CAMHS due to a lack of beds. In place of an admission, this young person's care was managed more intensively in the community with the support of social services but after a period of doing well her condition began to deteriorate. Five months after her referral episode she was admitted to a paediatric ward following an overdose and from there was admitted to a CAMHS unit.

4.2.3.4.3 Presented to A&E or admitted to a general medical ward

Thirty six young people presented at an accident or emergency department or were admitted to a general medical ward at some point before or after their referral episode (five young people had contact with these services both before and after their referral episode). For 22 (61%) of these young people their presentation was following a suicide attempt.

4.2.4 Comparison of the characteristics and service contacts of the young people referred from the two SHA areas

We compared young people, for whom we had full data, who had been subject to a referral episode in the East SHA (n=53) with those in London (n=52) for the range of study variables (see Tables and 4.7 and 4.8). The main differences were:

- A higher proportion of young people referred for IP CAMHS in London were from black and ethnic minority groups (31% in London vs 6% in the East; Chi=12.69; df=1; p<0.001).

- A higher proportion of young people referred in the East have an eating disorder (39% vs 5%; Chi=15.7; df=3; p<0.001).

- The group of young people referred from the London SHA had a significantly lower CGAS score (denoting greater severity of problem) than those referred from the East (32 [sd:10.2] in London compared with 39 [13.4] in the East; Mann Whitney U Test: z=-2.18; p<0.05). This difference was due to the high proportion of young people with an eating disorder in the East, who an average are given a higher CGAS than those of other diagnoses. When this group was removed from the analysis the difference between the two SHA areas was no longer significant (34 [sd 9.9] in the East compared with 32 [sd 10.2] in London).

- A significantly higher proportion of young people from the London SHA area had experienced some form of abuse (Chi=8.5; df=2; p<0.05).

There was no significant difference between those from the East SHA and from the London SHA in the number of services (mean of three) that young people had contact with either before (Mann Whitney U Test: z=0.52; p=0.61) or after referral (Mann Whitney U Test: z=0.02; p=0.81). There was also no significant difference found for the number of professionals (mean of three) they were in

contact with either before (mean of 4-Mann Whitney U Test: z=0.15; p=0.88) or after the referral (mean = 5 in the East and 4 in London-Mann Whitney U Test: z=1.33; p=0.18).

Table 4.7 Characteristics of those in the East and London SHA areas[1]

Young People's Characteristics		Number (%)*		Test of significance (FE=Fisher's Exact NS=Not significant)
		East (N=53)	London (N=52)	
Male		12 (23)	17 (33)	NS
Age 12-13		5 (9)	9 (17)	
Age 14-15		28 (53)	24 (46)	NS
Age 16-17		20 (38)	19 (37)	
White-British		48 (94)	36 (69)	Chi=10.60; df=1; p<0.01
BME groups		3 (6)	16 (31)	
Accommodation at time of referral	Living in the family home	40 (75)	30 (60)	
	Foster care/children's home	2 (4)	7 (14)	
	Independently/with relatives	2 (4)	3 (6)	
	Adult psychiatric ward	4 (8)	2 (4)	
	Paediatric ward	4 (8)	7 (14)	
	General medical ward	1 (2)	1 (2)	
Main carer	Both natural/adoptive parents	27 (51)	17 (33)	
	Single parent/natural parent & partner	21 (40)	21 (41)	
	Living with relatives	0	4 (8)	
	Foster care/children's home	4 (8)	9 (18)	
	Other (living independently)	1 (2)	0	
Source of referral	CAMHS psychiatrist	43 (81)	47 (90)	
	Other community CAMHS worker	3 (6)	2 (4)	
	General Practitioner	6 (11)	0	
	Accident and Emergency Dept.	0	1 (2)	
	Others	1 (2)	2 (4)	
Type of referral[2]	Emergency (within 24 hours)	21 (40)	27 (52)	
	Planned for assessment	20 (38)	13 (25)	
	Planned for treatment	18 (34)	19(37)	
Legal status	Children Act applied-yes	5 (9)	13 (26)	
	Mental Health Act applied-yes	10 (19)	9 (18)	
Diagnosis	Mood (affective) disorders	14 (28)	16 (31)	
	Eating disorders	20 (39)	2 (4)	
	Schizophrenia, delusional or psychotic disorders	4 (8)	7 (14)	
	Other diagnoses/not known	13 (26)	26 (51)	
Presence of learning disability	None	46 (87)	34 (71)	
	Specific learning difficulty	4 (7)	12 (25)	
	Generalised -mild (IQ 50 to 69)	3 (6)	1 (2)	
	Generalised but IQ not tested	0	1 (2)	
Clinical severity	CGAS score	39 sd=13.4	32 sd=10.2	Mann Whitney U Test: z= -2.33; p<0.05
	CGAS score missing	14	19	
	CGAS (without eating disorder)	34 sd=9.9	32 sd=10.2	Z=0.41; p=0.7 NS
Risk	Risk to self	37 (70)	34 (67)	NS
	Risk to others	1 (2)	3 (6)	
	Risk to both self and others	5 (9)	9 (18)	
	Not at risk to self or others	10 (19)	5 (10)	
	Suicidal attempt ever	15 (32)	15 (29)	
	Ever self-harmed	29 (58)	31 (62)	
	Presence of any abuse	13 (26)	27 (54)	Chi=6.74; df=1; p<0.01
Education	Attending some form of education	49 (73)	29 (76)	NS
	Excluded/suspended from school	9 (13)	7 (18)	

* Missing cases were excluded for the calculation of percentages.

Table 4.8 Type of services and professionals young people were in contact with six-months before and after referral in the two SHA areas

Types of services/professionals contacted	East SHA N=53 (%)		London SHA N=52 (%)	
	Pre-referral	Post-referral	Pre-referral	Post-referral
1 A&E or adult general medical ward	15 (28)	5 (9)	19 (37)	7 (13)
2 In-patient CAMHS unit	6 (11)	27 (51)	10 (19)	31 (60)
3 Day-patient CAMHS	2 (4)	1 (2)	0	5 (10)
4 Paediatric ward	15 (28)	5 (9)	14 (27)	3 (6)
5 Adult mental health ward	6 (11)	8 (15)	4 (8)	0
6 Community CAMHS	40 (75)	51 (10)	44 (85)	42 (81)
7 Community CAMHS psychiatrist	32 (60)	37 (70)	34 (65)	35 (67)
8 CAMHS CPN, outreach worker, primary mental health worker	21 (40)	39 (74)	7 (13)	4 (8)
9 Family or individual therapist (incl. art or occupational)	34 (64)	38 (72)	27 (52)	26 (50)
10 Clinical psychologist	13 (25)	1 (2)	7 (13)	0
11 Paediatrician (outpatient)	2 (4)		1 (2)	
12 Adult mental health teams	2 (4)	4 (8)	0	2 (4)
13 General practitioner	22 (42)	12 (23)	6 (12)	2 (4)
14 Dietician	4 (8)	3 (6)	0	0
15 Social worker	14 (26)	17 (32)	25 (48)	25 (48)
16 Children's home	2 (4)	0	4 (8)	3 (6)
17 Connexions	2 (4)	5 (9)	9 (17)	6 (12)
18 Educational services (welfare officer/psychologist, special educational needs co-ordinator)	13 (25)	13 (25)	23 (44)	13 (25)
19 Police custody or probation officer	1 (2)	1 (2)	9 (17)	2 (4)
20 Youth offending team	1 (2)	1 (2)	5 (10)	3 (6)

4.3 COMPONENT 2: CARE PATHS IN THE TWO YEARS FOLLOWING REFERRAL OF THOSE NOT ADMITTED

We obtained information about the subsequent care paths followed by 61 of the 69 young people (89%) who had not been admitted to the first CAMHS unit to which they had been referred. Of these, 28 were referred on and subsequently admitted to another unit during the referral episode. For the remaining 33 young people, their referral episode did not result in an admission to any IP CAMHS unit.

Table 4.9 summarises the level and quality of contact that these young people had with services over the two years following their referral episode, as judged by the clinician that provided information about the care path.   The only significant difference between young people who were subsequently admitted and those who were not is in parent's participation in the help offered. A higher proportion of parents of those subsequently admitted were reported to be engaged in the treatment offered than the parents of those not admitted to any unit ($z=1.99$; $p<0.05$). There were no statistical differences in the proportion of young people from each group who were described as moderately or actively participating in the treatment offered ($z=1.84$; $p > 0.05$) or those who refused to engage in treatment ($z=1.47$; $p > 0.05$).

Table 4.9 The frequency and quality of contact with community CAMHS during the 24 months after the referral episode for those not admitted to the first unit

Level of contact with community CAMHS in the two years after the referral episode	Young people not admitted to first unit to which they were referred		
	Referred on and admitted to another unit N=28 (%)	Not admitted to any unit N=33 (%)	Combined N=61 (%)
Overall frequency of contact:			
1 more than once a week	10 (36)	16 (48)	26 (43)
2 twice or once a month	4 (14)	7 (21)	11 (18)
3 some unknown amount of time	12 (43)	9 (27)	21 (34)
4 no contact with CAMHS	2 (7)	1 (3)	3 (5)
Number still in contact with CAMHS two years post date of referral episode:	9 (32)	15 (45)	24 (39)
Clinician's view of young person's co-operation with help offered and with keeping appointments:			
1 moderate to active participation	15 (54)	10 (30)	25 (41)
2 passive participation	1 (4)	3 (9)	4 (7)
3 complete or occasional refusal	10 (36)	18 (55)	28 (46)
4 missing data	2 (7)	2 (6)	4 (7)
Clinician's view of parents' co-operation with help offered and with keeping appointments:			
1 moderate to active participation	19 (68)	14 (42)	33 (54)
2 passive participation	4 (14)	5 (15)	9 (15)
3 complete or occasional refusal	3 (11)	7 (21)	10 (16)
4 missing data	2 (7)	6 (18)	8 (13)

4.3.1 Young people's functioning 24 months after the referral episode

We obtained clinical severity scores for only 27 of the 61 (44%) young people for whom we obtained care path data. The average CGAS score for this group, about 24 months after the date of their referral episode, was 56 (sd: 12.4) which indicates a good level of functioning. Clinicians were also asked whether, in their view, the young person's condition had improved since the date of their referral and responses were obtained for 55 of the 61 care path cases. Clinicians reported an improvement in the young person's condition for 21 of the 31 (68%) young people who were not admitted to any unit and 16 of 24 (67%) who were not admitted to the first unit but referred on to another unit.

4.3.2 Types of care path followed by young people who were not admitted to the first unit to which they were referred

As discussed in section 3.6.5, we reviewed all the information available, which included both categorical responses to questionnaire items and free-text descriptions of interactions with services, in an attempt to create a typology of care paths followed by those not admitted when first referred. Young people could be assigned to one of three themes: good engagement, poor engagement, and multiple admissions or transfers – within which there were a total of six types of care paths (see Figure 4.5).

Figure 4.5 Flow chart showing admission and non-admission pathways

Referred for Admission (n=159)

Referral outcome
(Missing n=3)

Admitted to first unit (65)

Not admitted to first unit (91)

Reasons for non-admission to first unit
(Missing n=22)

No bed available (22)

Other (5)

YP/Parent refused admission (26)

Not appropriate (9)

Improved (5)

Other (2)

(4)

(22)

Subsequent referral outcome

Admitted to another unit (31)

Not admitted to any unit (38)

Care paths within two years
(Missing n=8)

What happened up to 2 years after the first referral?
(Totals n=61; number not admitted to any unit n=33)

A. Good engagement with CAMHS (42; 19)

B. Poor engagement with CAMHS (19; 13)

A.1 Improved & discharged (10: 8)

A.2 In contact with CAMHS or Adult CMHT (22; 11)

(10)

(2)

C. Repeated referrals and more than one admission (incl. paed. or adult wards) or transfers for long-term treatment (12^{1}; 2^{2})

B.1 Improved & discharged (2; 1)

B.3 Case closed due to repeated non-attendance (8; 5)

B.2 In contact with CAMHS or referred on to other services (CMHT, YOT, SS care) (7; 5)

C.1 In contact with CAMHS or referred on to other services (CMHT, YOT, SS care) (11; 2)

4.3.3 Case descriptions of each care path typology

The vignettes that follow illustrate the care path types. They have been fully anonymised and we do not give the names of services, trusts or the SHA area in which the young person lives.

TYPE A.1: Good engagement with gradual reduction in CAMHS input leading to discharge from mental heath services (MHS).

Before referral
A female, aged 14 at the time of referral, had been under the care of her local community CAMHS team since she was 10 years old. Six-months before the study referral episode she had been admitted to a specialist eating disorder unit because she was not eating, had lost weight rapidly and was refusing to attend school. She had discharged herself after two weeks. Following this brief admission, the IP CAMHS unit provided outreach support including home visits and the young person attended weekly individual therapy sessions with a community CAMHS nurse. The young person had also been seen monthly by the community CAMHS psychiatrist for assessments and family work. Home tuition had been provided by the local education authority.

The index referral
Before the index referral, the young person had been admitted to a paediatric ward for more than a week because of medical problems (not related to her eating disorder). After discharge she continued to lose weight, refused to eat, and was no longer responding to CAMHS outpatient treatment. The CAMHS psychiatrist referred her again to a specialist eating disorder unit where she attended an assessment for treatment. She was offered a bed but declined it.

Subsequent care path
Outpatient care continued as before and she saw the community CAMHS nurse for weekly individual therapy sessions. As the young person's condition improved, the frequency of these sessions was reduced from weekly to every two weeks and then every month over five months. She was then seen every 10 weeks for follow-up assessments until no further treatment was required and she was discharged from the community CAMHS team 16 months after the study referral episode. She returned to mainstream school.

Clinician's view of the appropriateness of the care received:
The referring clinician thought that the "threat" of another period of hospitalisation had motivated the young person to engage more fully with treatment and to gain weight. The clinician felt that an appropriate and responsive care package was provided, and that the young person engaged successfully with the treatment programme offered.

TYPE A.2: Good engagement with continued and consistent input from the community CAMHS team

The index referral
A male, aged 14 at the time of referral, presented to his GP with depression and psychotic symptoms. The GP referred him to a community CAMHS team which assessed him as being at risk to himself. The community CAMHS psychiatrist made an emergency referral to an NHS general adolescent CAMHS unit within the SHA. No bed was available.

Subsequent care path
After the young person had been denied admission, the psychiatrist made subsequent referrals to two other units, both managed by the independent sector: one outside the region and one within the region. During the two days that a bed was being sought, intensive outreach care was provided by the community CAMHS consultant and a CAMHS outreach worker. The young person was admitted to an Independent sector unit within the region (but outside the SHA area) and remained an inpatient for four months. His mental health deteriorated following discharge due to continued use of substances and he was re-admitted to the same Independent sector unit for another four weeks of treatment.

The local CAMHS outreach worker maintained contact with the young person throughout his stay on the inpatient unit and provided follow-up following discharge. The care programme approach (CPA) was followed and involved CAMHS, a drug advisory team, education and social services. The young person engaged actively with the care provided and maintained weekly contact with the CAMHS outreach worker and saw the consultant psychiatrist once a month. Eighteen months after the index referral the young person was still receiving care from the community CAMHS team. He was living at home and receiving education on a home-tutoring scheme, after a period of absence from any form of education.

Clinician's view of the care provided
The clinician who provided the information thought that, following discharge, the young person had received an appropriate level of care after discharge and that the risk to self had been reduced.

TYPE B.1: Poor engagement but showed improvement and was discharged from the community CAMHS team

Before referral
A female, aged 14 at the time of referral, had been known to the community CAMHS team since she was at primary school. She had a range of behavioural problems and a primary diagnosis of an eating disorder. In the past she had been repeatedly admitted to a paediatric ward for treatment of diabetes. This young person also had a specific learning difficulty and an educational statement but was not attending any form education at the time of the referral episode.

The index referral
She was referred to a specialist eating disorder unit for IP CAMHS treatment because she was not responding to outpatient treatment and had engaged in a pattern of binge eating followed by unsafe starving. The clinician also reported that, at the time of the referral episode she was a risk to herself. In addition to

the eating disorder she had co-morbid problems relating to depression, anxiety and obsessive-compulsive disorder. The referral did not lead to an admission as she was assessed by the unit staff as not needing IP CAMHS care.

Subsequent care path
The community CAMHS team continued with outpatient care and offered weekly individual sessions with a clinical psychologist. Over a period of six-months the young person attended a total of just 11 sessions and then disengaged. Her case was closed six-months later (one year after the referral episode). While in contact with CAMHS, the young person also received home visits from a diabetes service and a Connexions and educational welfare officer arranged for home tutoring. She later engaged with a pupil referral unit.

Clinician's view of the care provided
The referrer thought that the young person was offered an appropriate level of care but that the care plan had not been fully implemented because the young person refused to engage and the parent was reluctant to support and participate in the treatment offered. At the last appointment the clinician was of the opinion that the young person's condition and functioning had improved and that she had re-engaged with education.

TYPE B.2i: Poor engagement but remained in contact with CAMHS after period of absence

Before referral
A male aged 13 at the time of referral had been known to the CAMHS team since he was 4 years old. He had been treated for ADHD, and co-morbid conduct disorder. Before to the referral episode, he had been attending monthly sessions with the community CAMHS psychiatrist and a family therapist. This young person has a specific learning difficulty and was attending a special school provided by the local educational authority. He was in regular contact with an educational psychologist who liaised between CAMHS and the school.

The index referral
This young person was referred to a local NHS general adolescent unit because he was not responding to outpatient treatment, was in conflict with his parents and had difficulty attending school. One of the main reasons reported for the referral was the need to achieve psychological separation from the parents. The IP CAMHS unit offered to undertake an assessment but this was declined by the young person and his parents.

Subsequent care path
No further referral was made for admission and the community CAMHS team continued to provide the same level of care as before with monthly sessions with the psychiatrist and a family therapist. The young person was reluctant to engage in treatment but the family were reported to be facilitative and actively engaged throughout. The young person attended some monthly sessions with the psychiatrist for one year after the referral episode. After this, the young person dropped out of contact. The family reported that the young person had improved and had started to attend school. Two years after the referral period, and a year after their last meeting, the family contacted the community CAMHS team again and were offered another appointment. This young person's case was never closed and continues to remain open to receiving care from the community CAMHS team.

Clinician's view of the care provided

The clinician thought that the young person would have benefited from intensive care in an IP CAMHS unit and that the overall outcome was not good.

TYPE B.2ii: Poor engagement dropping in and out of contact but with onward referral to other services

Before referral

A male, aged 15 at the time of referral, had been known to the community CAMHS team since he was at primary school. His contact with the community CAMHS team had been patchy and in the past he had been non-compliant to treatment. The young person had been excluded from a school for children with emotional, behavioural and social difficulties and, as a result, had received no education for more than one year. Social services had closed the case because they felt there was nothing else they could do. He had a primary diagnosis for a conduct disorder and co-morbid problems relating to an attention deficit hyperkinetic disorder and features from the autistic spectrum.

The index referral

The community CAMHS psychiatrist assessed the young person as posing a risk to both himself and other people and the family reported that they were no longer able to cope. The referrer thought that the young person required a secure placement and referred him to the local NHS general purpose unit. The unit assessed the young person but declined to admit him because of his history of assaults on others. It was also thought that he would not have accepted admission had it been offered. Those making the assessment did not think that it would have been appropriate to have admitted him under the Mental Health Act.

Subsequent care path

A few weeks after the initial assessment, the unit to which the young person had been referred offered him a place on its day-patient programme. Although at first he did not attend, the unit worked hard to engage him. This was successful and he attended the day-programme on a voluntary basis for seven months. For a further six months, he was engaged by another counselling and psychotherapy service that worked specifically with young people with difficult behaviours. This provided outreach home visits over this period. The last reported contact with services was with a Youth Offending Team (YOT).

Clinician's view of the care provided

The referrer thought that the young person would have benefited from admission to a secure unit but this could not be achieved unless he had been admitted under the Mental Health Act.

TYPE B.3: Poor engagement, dropping in and out of contact and case closed by CAMHS against advice

Before referral

The young person (female, aged 15 at the time of referral) had been receiving regular family therapy and individual therapy from a community CAMHS team over a period of four months. Her primary diagnosis was for a mood (affective) disorder but the clinician described a range of other co-morbid problems including self-harming behaviours, psychotic symptoms, and obsessional and body dysmorphic features.

The index referral
The referral for IP CAMHS was initiated when the young person presented at an emergency department after an attempted suicide. She was expressing suicidal ideas and had some psychotic symptoms. She was admitted to a paediatric ward. The emergency department contacted her community CAMHS team which made a referral to a local NHS general adolescent unit. No bed was available.

Subsequent care path
After she had been denied admission, the young person's community CAMHS team referred her to an independent sector general adolescent unit to which she was admitted, from the paediatric ward, two days after the attempted suicide. After one week on this unit, the young person was transferred to her local NHS general adolescent unit where she remained an inpatient for four months.

Following discharge, the community CAMHS team offered the young person monthly appointments with a psychiatrist and twice a month family therapy sessions. She and her family did not attend appointments and only contacted the service on one or two occasions. The family reported that the young person was doing well at home and had secured a place at college which she was attending. After a year of having no contact, the young person requested that the local community CAMHS team support her application for social housing. The CAMHS team remained concerned about her welfare and her ability to manage her medication, and so contacted her GP. The GP informed the team that the young person had moved to another area. The team transferred her care to the community CAMHS team close to where she was now living. This team offered the young person an appointment. We do not know whether she attended (this new appointment had been offered two years after the index referral).

Clinician's view of the care provided
The clinicians thought that this young person required more long-term treatment and, before she was discharged from the CAMHS inpatient unit, had sought admission to the local NHS medium-stay CAMHS. The young person declined an offer of a bed. The community CAMHS team continued to believe that this young person would have benefited from a longer-term treatment package, but she refused to engage. Two years post the referral episode there was still concern for her wellbeing.

TYPE C.1: Repeated referrals, admissions, and transfers for longer-term treatment

Before referral
A female, aged 14 at the time of referral, had been receiving care from a community CAMHS team for six-months. During this time her condition worsened, she had stopped attending school and had taken an overdose. Her family felt they could no longer cope. The young person's primary diagnosis was of stress-related and somatoform disorder. The community CAMHS consultant psychiatrist also thought that she might have a non-specified eating disorder.

The index referral
Because of concern about her worsening condition and poor functioning, the community CAMHS psychiatrist referred her to a local NHS general adolescent unit. This unit had no bed available.

Subsequent care path

After being declined admission, the community psychiatrist referred the young person on to another NHS general adolescent unit. However, this second referral was not pursued and the community CAMHS team decided to attempt to manage the young person themselves with the support of social services. She engaged in a programme that consisted of weekly sessions with a psychotherapist, family work with a social worker attached to the CAMHS team and regular appointments with a psychiatrist. The young person appeared to improve over the next four months but then started to disengage and her condition worsened. At this time it was thought that she posed a risk to herself and to others and so a third referral was made, and she was admitted to a local NHS general adolescent unit. She remained an inpatient for nine months. The young person then discharged herself against the advice of the inpatient unit staff who thought that they could not detain her under the Mental Health Act. Shortly after discharge, the young person was admitted to a paediatric ward for two weeks and then transferred to a specialist eating disorder unit. This placement broke down and she was discharged after one month. Ten days later she was admitted again; this time under Section 3 of the Mental Health Act to a different specialist eating disorder unit outside of the region. Five months later (two years after her initial referral episode) the young person was still an inpatient at this unit.

Clinician's view of the care provided

The community CAMHS psychiatrist thought that the most appropriate form of care, for this young person's severe and chronic problems, would have been multi-agency, intensive outreach work with the support of specialist respite foster care. The admissions to IP CAMHS did not appear to work and the young person appeared to regress with each admission. Overall her condition had not improved two years after her first referral.

4.4 COMPONENT 3: YOUNG PEOPLE AND PARENTS' EXPERIENCES OF THE CARE PATHS FOLLOWED.

Due to the delays encountered during this study and the complexities involved in obtaining consent from young people two years post the date of their referral, it was not possible to complete this component of the study.

4.5 COMPONENT 4: CRITERIA TO DEFINE WHAT CONSTITUTES 'APPROPRIATENESS' FOR ADMISSION

4.5.1 Main themes to emerge from the literature review (see Appendix A 1.5) and the group interview

The five themes most frequently raised related to risk and severity of problems were:

- presence of severe dysfunction;
- high level of risk to self;
- high level of risk to others if in the context of a mental illness;
- need for 24-hour observation;
- need for intensive treatment.

Other themes were:

- tier 3 options exhausted/young person cannot be managed in the community – dependent on resources;
- parents' ability to cope and their expectation of treatment;
- belief that the problems experienced by a young person would be helped by admission;
- engagement with the young person and family;
- the most vulnerable young person may not be accessing IP care, particularly males who are not verbally skilled and use behaviour to express themselves;
- the impact and importance of the focused educational input received during IP treatment.

4.5.2 Agreement on criteria for admission based on the results from two ratings.

4.5.2.1 Participants – Demographic information

For the first survey rating, responses were received from a total of 169 of the 385 (44%) CAMHS professionals who were surveyed. The group that responded comprised 102 professionals who worked in inpatient settings (56% of those surveyed) and 67 who worked in the community (33% of those surveyed).

Ninety-five of the 169 (56%) respondents to the first survey also responded to the second – 56 inpatient professionals and 36 community professionals. Table 4.11 summarises the basic characteristics of the samples.

Table 4.10 Characteristics of the 169 respondents to the first criteria for admission survey and the 95 respondents of the second admission survey

	1st Survey Frequency (%)	2nd Survey Frequency
Male	82 (49)	49 (52)
Female	87 (51)	46 (48)
Psychiatrist	94 (56)	59 (62)
Nurse	54 (32)	25 (26)
Other	21 (12)	11 (12)
IP Unit	102 (60)	56 (62)
Community CAMHS	67 (40)	36 (38)

4.5.2.2 Responses to the two surveys

Table 4.12 summarises responses to the first section of the questionnaire which asked categorical questions about whether the professional would or would not consider admitting, or requesting admission for, a young person with certain types of problem.

Table 4.11 Percentage of respondents who would admit young people with particular types of disorder

Items	% who stated that they would admit	
	1st Survey	2nd Survey
An adolescent who you thought **did not have a severe mental illness**?	44	48
If the young person presented with challenging behaviours or conduct disorder in the **absence** of a severe mental illness?	23	22
If the <u>primary</u> problem was a substance misuse problem?	17	22
If the <u>primary</u> problem was a development disorder?	37	52
If the <u>primary</u> problem was learning disability?	16	36

Section 2 of the questionnaire asked participants to rate the importance (on a scale where 1=not at all important to 5=of major importance to their decision to admit and 6=main determinant combined with the presence of severe mental illness) of a range of factors in determining whether a young person, who has a severe mental illness, is appropriate for admission to either a general adolescent or specialist eating disorder unit. Table 4.13 summarises the results with factors listed in order of their importance as indicated by the results of the first survey.

The only factor for which the mean score differed significantly between the two survey points was "violent behaviour" (paired t-test, $p<0.05$).

4.5.2.3 Agreement between the two survey responses for IP CAMHS and Outpatient CAMHS professionals and for Nurses and Psychiatrists

The agreement between the two surveys about the importance of a particular criterion (considered important or not) was assessed using Kappa coefficients (a coefficient is used to measure the agreement between two values). We assessed the level of agreement between the two ratings for IP and outpatient CAMHS professionals and for nurses and psychiatrists.

The agreement for individual items between the two surveys was moderate (Kappa coefficient 0.4 to 0.59) for both IP CAMHS and outpatient professionals for 11 out of 17 admission criteria. However, the pattern of agreement between the two surveys differed for psychiatrists and nurses. Psychiatrists showed a moderate to substantial level of agreement (kappa coefficient 0.6 to 0.79) between the two ratings for 12 out of 17 items. Nurses showed moderate agreement for just 7 out of 17 items. This indicates that nurses may be influenced on admission criteria, if the previous survey results are provided.

Table 4.12 The criteria for admission in rank order of importance with the mean rating scores and percentage of participants who considered each criterion to be of importance to their decision to admit

RANKING	ITEMS arranged in order of their importance in the First survey	Mean (SD) of scores		% of participants considered the factor as important	
	High level of consensus for factors of *major* importance	1st Survey	2nd Survey	1st Survey	2nd Survey
1	Risk of suicide	5.2 (1.0)	5.2 (0.7)	95	98
2	Physical health is deteriorating due to mental illness (e.g. very low body weight, severe self neglect, reluctance to eat or drink etc).	5.1 (1.0)	5.1 (0.8)	91	98
3	Need for 24-hour a day observation to develop a care plan due to the complexity of the case	4.7 (1.0)	4.7 (0.9)	88	93
3	Presence of serious self-harm (evidence of active self-harming causing serious injury)	4.6 (1.1)	4.4 (1.0)	88	85
4	Unresponsive to outpatient care	4.1 (1.0)	4.1 (0.8)	76	82
5	Young person's willingness or desire to engage in the treatment package	4.0 (1.0)	4.0 (0.8)	73	81
6	Inadequate family support or family unable to cope	3.9 (1.1)	3.9 (1.0)	69	72
7	An assessment needs to take place away from the family or usual environment	4.0 (1.0)	3.9 (0.9)	67	79
8	Risk to others (e.g. fire-setting, sexual abuse etc.)	3.6 (1.4)	3.7 (1.4)	56	73
9	Young person's reluctance to engage with outpatient treatment	3.5 (1.1)	3.6 (1.0)	55	63
10	Low level of functioning as indicated by a low CGAS score or a high HoNOSCA score	3.6 (1.2)	3.6 (1.0)	54	62

RANKING	ITEMS arranged in order of their importance in the First survey	Mean (SD) of scores		% of participants considered the factor as important	
	High level of consensus for factors of *major* importance	1st Survey	2nd Survey	1st Survey	2nd Survey
11	Separation from the parents or family would be of benefit to the young person	3.5 (1.1)	3.7 (0.9)	50	64
12	Violent behaviour	3.2 (1.4)	3.7 (1.2)	46	62
13	Parents' desire for admission	3.4 (1.0)	3.7 (0.7)	44	40
13	* Co-morbid presence of a developmental disorder (e.g. Aspergers Syndrome, Autism)	3.2 (1.0)	3.2 (0.8)	39	34
14	Co-morbid presence of substance misuse problems	3.1 (1.1)	3.1 (0.9)	33	26
15	Co-morbid presence of a learning disability	2.9 (1.1)	2.8 (1.0)	23	18

5. DISCUSSION

5.1 LIMITATIONS OF THE STUDY

We had intended to track prospectively the care paths of young people referred but not admitted to IP CAMHS. This did not prove possible because of changes in the national research ethics and research governance processes (see Chapter 3 and Appendix 4.1). The data collection methods were amended and the data were collected retrospectively. This, and delays caused by the new research ethics and governance processes, affected both the completeness and the quality of the data.

5.1.1 Completeness of the data

The plan had been to capture information about young people referred from four population bases, two with high levels of CAMHS inpatient provision and two with low provision relative to the levels recommended by the Royal College of Psychiatrists (2005). We collected sufficient data for analysis from only two of these populations, one with high and one with low provision. Although comparisons between these two areas are worthwhile, a second pair of sites would have allowed us to confirm or refute some of our findings.

We collected detailed information for two-thirds of the young people who had been referred. This group contained a higher proportion of young people who had more than one referral during their referral episode than did the group for whom detailed information was not collected (32% compared with 7%). However, the details of whether or not more than one referral was made were often obtained from the questionnaire data and this difference could simply be an artefact of the lack of data on whether other referrals were made for the 'no questionnaire data' group.

5.1.2 Quality of the data

The main questionnaire and care path data were collected some time after the date of the referral episode. Although we attempted to mitigate the effect of this by requesting that clinicians refer to the casenotes, this might have adversely affected the quality of the data and, in particular, data relating to clinical severity at the time of the referral episode.

5.1.3 A partial view of the problem

The index event for entry into this study is the referral episode for IP CAMHS. Thus we only identified those young people admitted to a paediatric or adult mental health ward who had also been referred to a CAMHS unit during the recruitment phase of the study. It is possible, and probably likely, that there are young people admitted into paediatric and adult mental health wards who are not also referred to a CAMHS inpatient unit. Also, the study only picked up those referred. It is possible that there were young people who might have benefited from inpatient care who were not referred because of a perception among community CAMHS workers that a bed would not be available.

A further limitation of the study design is the lack of outcome data. The collection of these data would have provided important standardised information

about how the young people fared throughout their care path in terms of their level of functioning and wellbeing. Through the retrospective data collection we did however, seek to obtain follow-up CGAS scores if they were recorded in the young person's case-notes and obtained the clinician's view on how the young person had fared. These scores however are only provided by the clinician and it could be argued that these are subject to bias towards wishing to show improvements.

5.2 DISCUSSION

5.2.1 Differences in demand for IP CAMHS beds between the two SHA areas

During the six-month study recruitment period, the rate of referral was more than twice as high in the London SHA than in the East SHA (90 vs 39 per 100,000 12 to 18 year olds). There are three possible explanations, more than one of which might apply:

1. **There could be greater need for IP CAMHS in the London SHA population**. The prevalence of mental disorders in children and young people, and therefore need for care, varies by more than two-fold between areas with high and low levels of social deprivation (Meltzer et al., 2000; Wallace et al., 1997). The London Region is ranked the fourth most deprived of the nine regions in England compared with the Eastern Region which is ranked seventh (Office of the Deputy Prime Minister, 2004).

2. **The greater demand for IP CAMHS in London could be due to better recognition of young people who would benefit from IP CAMHS**. London has good provision of specialist adolescent outreach teams, which exist in addition to community CAMHS teams (see Appendix A 5.0). In contrast, in the Eastern Region, some community services still have a cut-off age of 16 years. In these services, care is transferred to adult mental health services after the young person reaches their 16th birthday.

   Compared with the East, the adolescent outreach teams in London may have identified more young people who would benefit from a more intensive level of care. This might have accounted for the higher referral rates of young people aged 16 and 17 old. Also, in the East, it is possible that a higher proportion of 16 and 17 year olds would already have been receiving care from adult services and so might have been admitted directly to an adult ward, without first having been referred to a CAMHS unit, had admission been required.

3. **Demand for admission could be driven by supply of beds.** The two SHA areas in this study were selected because they were located in regions that differed in the amount of IP CAMHS provision. The London SHA is located in a region that had, during the study period in 2005, 40 adolescent CAMHS beds per 100,000 of the 12-18 year old population (28.5 per 100,000 of these beds are in general adolescent units). The equivalent figure for the regional beds accessed by the East SHA area was 12.4 beds per 100,000 12 to 18 year olds (10.3 per 100,000 are in general adolescent units).

One possible explanation for the difference in referral rates is that referring clinicians in London, influenced by greater availability of beds, might have a lower threshold for requesting IP CAMHS. However, two of the findings do not support this. Firstly, the average CGAS score for the young people referred in London is significantly lower, indicating a more severe level of functioning, than the average score for those referred from the East SHA area (32 in London compared with 39 in the East). Secondly, similar proportions of young people in the East and in London were denied admission to the first unit to which they were referred. The latter suggests that the two areas do not differ in terms of bed availability, as would be perceived by referrers.

There is one group of young people for whom demand, as expressed by referral rates, might have been influenced by supply of beds. Unlike the London SHA (which has access to two large independent sector eating disorder units) the East SHA has an NHS eating disorders unit. This might have accounted partly for the finding that many more young people with an eating disorder were referred for admission in the East than was the case in London (23 of 73 referrals in the East compared with one of 86 referrals in London) where the focus of care for eating disorders is specialist outpatient services. The question of which type of care produces the best outcome for this group has recently been examined. The Trials of Outcomes for Child and Adolescent Anorexia Nervosa (TOUCAN) study undertook a randomised control trial to evaluate the clinical and cost effectiveness of three treatments for young people with anorexia nervosa. The young people (n=167 12 to 18 year olds) were randomized to one of three treatment groups: specialist inpatient treatment, specialist outpatient treatment and treatment from a generic tier three CAMHS. The specialist outpatient treatment service was reported to be the most cost effective treatment option (Gowers et al., 2007; Byford et al., 2007).

5.2.2 Admissions outside of the region

One of the standards in the Children's NSF is to provide services close to the young person's home (Department of Health and Department of Education and Skills, 2004). This is important for inpatient care for two reasons. First, it allows the young person to better maintain contact with family, friends and local community supports. Second, it enables better communication with local services, particularly around the time of discharge. The behaviour of referrers is consistent with the NSF standard. Overall, the general pattern was for the first referral to be made to the local NHS unit. If this was unsuccessful, the onward referral was to an independent sector unit within the region. Generally, young people were only referred to an independent sector unit outside the region once these avenues had been exhausted.

Despite the differences in the supply, demand and need in the two SHA areas, similar proportions of young people were admitted to the first unit to which they had been referred (44% in London vs 37% in the East). Also, similar proportions of those who were not admitted to the first unit were referred on to another unit (23% in London vs 25% in the East). However, referrals and admissions to units outside the region almost exclusively were from the East SHA. Here, more than

one-third of those denied admission to the first unit were eventually admitted to a unit outside the region, compared with just one young person in London.

The most obvious explanation is that the Eastern Region has fewer beds and so has to make more use of beds outside of the region. However, as argued above, there is no evidence that, although there are more beds in London, they are any more available to referrers. An alternative or complementary explanation, which was suggested by more than one clinician, is that, due to the nature of transport links, for some families, units in London are more accessible than units in distant parts of the Eastern Region.

5.2.3 The role of the Independent sector

Since 1999 the number of IP CAMHS beds in England has increased by 34%. More than two-thirds of these new beds are provided by the Independent sector which now manages one-third of all CAMHS beds in England (See Appendix 4.2; O'Herlihy et al., 2007). The finding that, although most first referrals are to the NHS, most second and subsequent referrals are to the independent sector, is consistent with the view that the independent sector has responded to market forces and is picking up the shortfall of beds in the NHS. Overall, the NHS units admitted far fewer of the young people referred to them than did the independent sector units (27% vs 89% of all referrals received). This might be due simply to the fact that, being the first point of referral, NHS units are invariably full. However, it might also partly reflect different incentive systems whereby the Independent sector has strong financial reasons for accepting admissions. One hypothesis would be that the independent sector would accept all referrals received and that their threshold for admission is lower than that of the NHS. The COSI-CAPS study will test this hypothesis by comparing the characteristics of those admitted to independent sector and NHS beds.

5.2.4 The impact of the lack of emergency provision

The Children's NSF (Department of Health and Department of Education and Skills, 2004) sets out a proxy target to improve 24 hour access and emergency cover in CAMHS by the end of 2006. In a recent report on its compliance with the UN Convention on the Rights of the Child, the Government states that, in relation to mental health services for adolescents: "In England, the Department of Health [will] ensure that all young people who need them have access to a range of services to tackle mental health problems and emotional well-being by 2006. Significant progress has been made towards that target, and by the end 2006-07 all 152 Primary Care Trusts in England reported 24 hour cover available for urgent needs and specialist assessments undertaken within 24 hrs or during the next working day" (UK Government Report to the UN Convention on the Rights of the Child, 2007, paragraph 29 page 91). The Government has also encouraged local service commissioners to raise their expectations in relation to better access and greater choice for all mental health service users including young people.

There has been much discussion about the capacity of inpatient CAMHS units to accept and manage emergency referrals and it is one of the main priorities for referring clinicians in the community (Corrigall and Mitchell, 2002; Cotgrove, 1997; Gowers et al., 1991). This study suggests that services in these two areas have neither met the aspiration of the NSF nor complied fully with the UN Convention with respect to this important element of service for young people with "urgent needs". A survey of provision for emergency admissions

undertaken in 2005 suggests that this is a problem in other parts of England (Cotgrove et al., 2007) – see below.

In this study, the referrer had requested emergency admission for 41 of the 67 young people who were admitted during the referral episode.   Only 20 of these young people were admitted to the first unit to which they had been referred (18 of these were admitted within 24 hours or the next working day). A single, local, acute NHS unit accepted 11 of the 14 such admissions in London. The 21 young people who had been referred as emergencies but denied admission had to be referred on to a second and sometimes a third unit. Nine of this group had to wait between two and seven days for a bed to be found. All but one of the 21 young people who, despite being an emergency, were denied admission by the first unit, were eventually admitted to a unit managed by the independent sector. Five of these were later transferred back to an NHS unit.

The findings of the survey of emergency provision undertaken in 2005 are consistent with the above and would support the view that this is also a problem in other parts of the country. The survey found that, while there has been an increase in the number of units with dedicated emergency beds from six in 2000 to sixteen units in 2005, the majority of units still had no such beds in 2005 and so could not accept admissions at short notice (Cotgrove et al., 2007).

5.2.5 Admissions to adult mental health wards

We found that, during the 6 months before referral to inpatient CAMHS, 16% of young people were admitted to an adult ward during the six months before or after referral for inpatient CAMHS. A substantial proportion of young people had also had contact with emergency departments and/or admission to general medical wards. This picture echoes the report of the Office of the Children's Commissioner (2007) which identified the 'inadequate response to crises …to which CAMHS is unable to respond' as a major contributor to the problem.

In the introduction and appendix A 1.0 (section A 1.4.4.2) we discuss research about the admission of young people to adult mental health wards for the treatment of mental health problems (Gowers et al., 2001; MHAC, 2004; Worrrall et al., 2004). Many such admissions are viewed to be inappropriate because such wards are often unable to meet the psychosocial, educational and developmental needs of young people and/or to provide a safe and secure environment. A recent report from the Office of the Children's Commissioner (2007) is more specific about the poor quality of care that young people receive on adult mental health wards. The report identified four themes: i. 'a lack of involvement in care planning'; ii. 'lack of peer-support or having someone to talk to'; iii. 'lack of safety, security and therapeutic care'; iv. 'disorganised discharge arrangements'. These themes are the opposite of what young people report to be helpful about receiving treatment in IP CAMHS unit.   In this setting, young people greatly value the support from staff and peers, involvement in decision making and the sense of being safe (Hart et al., 2003).

The Mental Health Act Commission (2004) concluded that admissions to adult mental health wards are a direct result of a shortage of CAMHS beds and a lack of emergency provision.   Such admissions will be illegal when the 'age-appropriate' environment amendment in the Mental Health Act 2007 is enacted. This stipulates that no child under 16 years of age should be treated on an adult ward and that all hospital managers have a duty to provide an age-appropriate

environment for young people under 18 years who are admitted to hospital (subject to need).

Elimination of the unacceptable use of adult mental health wards will take time to allow commissioners and providers to plan and develop alternative services. Since the Mental Health Act 2007 was enacted there has been a Ministerial commitment to eliminate the admission of children under 16 within two years. Where a child under 16 is placed, mental health provider Trusts are expected to treat this as a Serious Untoward Incident (SUI) and report it to the Strategic Health Authority (SHA). There is an expectation that the SUI will make clear how the child's needs are to be met, what the exit strategy to CAMHS is and what the safeguarding arrangements are. The SHA then reports the SUI directly to the Department of Health as an MB Alert (the system whereby SHAs alert Department of any local issues that may attract media attention). SHA directors of performance have written to chief executives setting out these new reporting requirements. For 16/17 year olds, reporting the incident to DH is not required. However, SHAs will want to check that 16/17 year olds are placed on adult wards only when appropriate, in line with best practice set out in the NSF, and decide locally what performance management of Trusts and PCTs is needed to ensure that this is achieved.

5.2.6 The challenges in meeting the needs of 16 and 17 year old males

The NICAP and CHYPIE studies, and more recently the COSI-CAPS study, found that two-thirds (62%) of those admitted to IP CAMHS are female (Jacobs et al., 2004; O'Herlihy et al., 2001; Tulloch et al., *in submission*). This study found that an even higher proportion of those referred for admission to a CAMHS inpatient unit are female (72%). In contrast, the Mental Health Act Commission (2004) found that of the 270 notifications they received 65% of under 18s detained under the Act on an adult mental ward were male.

Although study numbers are small, it is striking that 12 of the 17 young people in this study who were admitted to an adult mental health ward were female. This might suggest that adolescent boys who are admitted to an adult ward are more likely to follow a route that by-passes referral to a CAMHS inpatient unit than do adolescent girls. If this is the case, it is important to determine why young males who need inpatient care are not being referred to IP CAMHS. We speculate that there might be a number of reasons: i. young men might be more likely to present with the type of problem that requires urgent intervention; ii. young men might present with problems that are perceived to be difficult to manage on an adolescent unit; iii. young men might engage less well with community CAMHS services and so be less liable for referral to inpatient CAMHS.

5.2.7 Differences between those admitted and those not admitted

For about two-thirds of young people, the referral episode culminated in an admission. Those who were admitted as a result of the referral episode were more likely to have been referred as an emergency, were more likely to have made a suicide attempt, had more severe problems, as measured by CGAS, and were less likely to have an eating disorder.

For most of the group of young people who were not admitted, the decision not to admit was made following the first referral. This might suggest that, although

their referral did not result in admission, the referral did serve some purpose that might have contributed to the resolution of an immediate problem.

5.2.8 The care paths of those not admitted

As illustrated by the vignettes in section 4.3.3, for many of the young people, this study examined a section of a longer care episode. These young people's problems predated the first referral for admission and continued long after the referral episode finished. This was true whether or not the young person was admitted. As a group, adolescents referred for admission have contact with multiple agencies and professionals and sometimes cross the interface between CAMHS and adult services in a way that justifies the call for greater integration between CAMHS and adult mental health services.

While two-thirds remained in contact with services two years after their referral episode a small number (8) disengaged from the care offered. It was unfortunate that we were unable to interview some of these young people about what they would have found helpful and their level of engagement with CAMHS. However, the Children's NSF progress report (Department of Health, 2007 page 58) reports on the emerging findings of a DH funded project 'CAMHS Choice 4 U' which found that:

- *access to services is improved when individual staff encourage engagement and services empower young people rather than telling them what to do;*
- *young people want a choice of locations and times;*
- *sharing information makes young people feel they have more choice; and poor communication within multidisciplinary teams restricts choice (Department of Health, 2007 page 58).*

Although the four interviews we conducted are not reported here, these areas very much reflect the issues these four young people raised.

Eleven of the 61 young people not admitted followed complex care paths following their referral episode, and a number were admitted to different inpatient environments over the follow-up two years. Again this is an artefact of not accessing an appropriate bed in an emergency, leading to an admission elsewhere and a later transfer to the CAMHS unit they were first referred to. As a group these young people continued to need CAMHS/other service input two years after the initial referral. Efforts need to be made to keep the care as consistent and local as possible.

5.2.9 Factors that influence decisions to admit

The surveys conducted as part of the modified Delphi procedure showed that there was a lack of agreement about who should be admitted in terms of diagnostic category. About one-half of respondents thought it appropriate to admit young people who would not be categorised as having a severe mental illness and one-half would admit young people with a developmental disorder. It is perhaps surprising that half of clinicians who either refer or make decisions about admission think it appropriate to admit young people who do not have a diagnosis that is consistent with severe mental illness. In this they are at odds with the criteria for admission recommended by, for example, the Scottish Executive. There was greater agreement on the inappropriateness of admitting young people whose primary problem was conduct disorder or substance misuse.

In contrast to the findings about diagnosis, there was a high level of agreement about the contextual factors that influence decisions to admit independent of diagnosis. This study suggests that the single factor that most influences the decision to admit is risk to self. Although this mainly relates to risk of suicide, severe risk to physical health, for example through malnutrition, is also important. The importance of risk to self is supported both by the finding that young people who had attempted suicide were 13 times more likely to be admitted and by the fact that risk of suicide and risk to physical health emerged as the two most highly rated criteria in the consensus exercise. Furthermore, the presence of serious self-harm was the fourth most highly rated criterion. these findings are consistent with other studies that aimed to identify the factors that predict an inpatient admission to a CAMHS unit (Bickman et al., 1996; Gutterman et al., 1993; Hillard et al., 1988) and with descriptive reasons reported for admission in the UK literature (Cotgrove and Gowers, 1999 & 2001; Green, 2002; NICE, 2005; Wrate et al., 1994).

Thus, any service that was set up with the intention of providing an alternative to admission for adolescents would, first and foremost, have to provide care in a manner that would reduce and manage risk to self or would be perceived by referring clinicians as doing this. If it failed to do that, it is likely that the service would not have a great impact on demand for admission.

There was broad consensus on a range of other contextual factors that favour admission including the ability of an inpatient unit to provide 24-hour observation and more in-depth assessment, greater opportunities to engage the young person in care and the removal of a young person from a home environment that may be potentially damaging or where other family members might not be coping. The latter is perhaps surprising because placement of a young person due to other family members are not coping is not a child centred intervention. However, it should be remembered that this factor was only thought to favour admission for children who had a severe mental illness.

There was a substantial level of agreement among psychiatrists about the factors that indicate the need for admission. This agreement involved psychiatrists that worked both in community and in inpatient settings. This would suggest that it might be possible to take the work on admission criteria one step further to create a set of operational criteria. These might, in turn, be the basis for benchmarking of "admission casemix" across wards and for evaluating the application of criteria for admission, including in the independent sector, perhaps to support better commissioning of this expensive and scarce element of service.

6. CONCLUSIONS AND RECOMMENDATIONS

6.1 CONCLUSIONS

1. The higher overall rate in London is probably due to greater need for CAMHS inpatient care rather than because demand is being driven by a greater supply of beds.

2. The higher rate of referral in the East of young people with an eating disorder is probably influenced by the presence of an NHS eating disorders unit.

3. The higher rate of admission to units outside of the region in the East is partly due to the relatively low number of beds in the region.

4. Nearly two-thirds of all admissions were to units managed by the independent sector, which acts as a "sump" for onward referrals from NHS units that cannot offer a bed.

5. Independent sector units are much less likely to turn away a referral than are NHS units.

6. Emergency admissions are being delayed because of problems of bed availability in NHS units. This is contrary to the Government's PSA target (Department of Health, 2004; Department of Health and the Department for Education and Skills, 2006) and expectations that local service commissioners have in relation to improved access and greater choice, and is not consistent with the Department of Health's assertion that there is 24-hour cover for urgent needs or specialist assessments across the country (UK Government, 2007).

7. The young people who are not admitted have high levels of contact with services, including adult services, both before and after the referral episode.

8. A significant number of young people referred to CAMHS inpatient units have admissions to adult mental health wards before and/or after referral. In future, many such admissions are likely to be in breach of the new amendment in the Mental Health Act 2007 which requires that young people have access to appropriate care in an environment suited to their age and developmental.

9. Although our study numbers are small, in contrast to other surveys that show that more males under age 18 than females are admitted to adult wards, there was a preponderance of females in the group that were admitted to adult mental health wards. This might suggest that young men are more likely to by-pass referral to CAMHS inpatient care on their pathway into an adult ward.

10. Risk to self is by far the strongest factor that influences decisions to admit. Any service for young people that is established with the intention of preventing admissions must, first and foremost, provide care that reduces the risk of harm coming to the young person or at least is believed to do so by clinicians making referrals.

6.2 RECOMMENDATIONS

1. The Department of Health might develop the findings of this study by commissioning work to reach formal agreement with clinicians responsible for admission decisions about criteria that determine appropriateness of admission to IP CAMHS. This work might also be informed by the criteria developed by the Scottish Executive (2005). Criteria would include those relating to diagnosis/problem type and to a wide range of contextual factors. The latter would include risk posed to and by the young person, their social and family situation, and the availability or otherwise of community-based services that might act as an alternative to admission.

2. Once the criteria have been developed, clinicians working in both community and inpatient CAMHS should be encouraged to audit their practice in relation to local admission decisions. The audit should include both NHS and Independent sector units.

3. The problem of delays in emergency admissions is likely to be compounded as demand increases due to pressure to implement the requirement of the Mental Health Act 2007 that young people are admitted to an age-appropriate setting. Unless the ability of NHS units to accept same day admissions, including out of hours, has greatly increased since this study, and a national survey conducted in 2005 (Cotgrove et al., 2007), most such admissions will be to independent sector units. Commissioners must ensure that procedures are in place to guarantee that adequate liaison occurs between the independent sector unit and local NHS services to ensure continuity of care for these very vulnerable young people.

4. Services that are developed as alternatives to admission must be capable of providing safe care to young people who are assessed as being at risk of self-harm and/or suicide if they are to substantially reduce demand for inpatient care.

5. To identify those most vulnerable to not accessing IP care, the Department of Health need to audit all those aged under 18 who present to other health settings (A&E departments, adult psychiatric or paediatric wards) and who require a psychiatric assessment. To inform planning it would be necessary to identify their routes into these settings and their prior, if any, contact with CAMHS and then track the care path they follow subsequent to the assessment. This group of young people should also be interviewed about their access to mental health services. This could be achieved through an audit and service evaluation project.

APPENDICES

A 1 LITERATURE REVIEW

A 2 REFERENCES

A 3 CIRS DATA COLLECTION TOOLS

A 4 RELATED PAPERS

A 5 OUTLINE OF CAMHS FOR TWO OF THE FOUR SHA AREAS

A.1 LITERATURE REVIEW

A 1.1 INTRODUCTION

The literature review aims to:

- Provide an overview of the policy on the provision of inpatient (IP) CAMHS and plans to address service gaps.
- Examine the potential demand for IP CAMHS beds by examining prevalence rates for severe mental illness among young people, and how this compares to the characteristics of those admitted.
- To describe how IP CAMHS provision for adolescents has changed between 1999 and 2006 and what is known about gaps in provision.
- To summarise the literature about reasons for, and determinants of, admission in the UK and the US and identify the factors that need to be considered in the study.
- To examine the literature on the care paths of young people who require treatment for severe mental illness, and about the views of users and carers.
- Provide a conclusion

A 1.2 CAMHS POLICY FOR INPATIENT SERVICES

A 1.2.1 Policy context

The development of Government policy over the past ten years is evidence of a growing commitment to CAMHS. The Government indicated its intention by publishing a CAMHS handbook as part of the *Health of the Nation programme* (Department of Health, 1995).

The Green Paper *Every Child Matters and Youth Matters* (Department for Education and Skills, 2003) describes the Government's current policy to improve the wellbeing of all young people. For CAMHS, a Public Service Agreement (PSA) target was set to provide a comprehensive service by 2006 and a commitment was made in the NHS planning and priority framework to increase provision annually by 10% between 2003 and 2006 (Department of Health, 2002). Indicator 4 in the most recent Public Sector Agreement relates to emotional health and wellbeing, and child and adolescent mental heath services (CAMHS). The proxy measures for this indicator include: appropriate accommodation and support for 16/17 year olds; availability of 24 hour cover to meet urgent mental health needs; and joint commissioning of early intervention support (HM Government, 2007).

A 1.2.2 Children's NSF–Standard 9

The Government set out its plan to use service standards, good clinical governance, and evidence-based guidelines to improve quality of care in 1998

(Department of Health, 1998). The subsequent NHS plan (Department of Health, 2000), which covered all forms of healthcare, outlined a ten-year strategy to:

- increase funding,
- *'redress'* geographical inequalities, and
- improve standards of care and patient choice.

National service frameworks (NSF) are one vehicle for supporting the implementation of the NHS Plan. They define standards of care that individuals can expect from services, and by which the quality of care provided by trusts could be assessed. Concerns about the care and wellbeing of young people, heightened by two tragic events - the death of Victoria Climbie and events at the Bristol Royal Infirmary, led to an urgent call for an NSF for children and young people. The Victoria Climbie Inquiry highlighted the failure of all services (health, education and social services) to protect vulnerable children and the Bristol Royal Infirmary Inquiry strongly recommended that priority be given to child healthcare services (Kennedy, 2001; Lord Laming, 2003).

The National Service Framework for Children, Young People and Maternity Services (otherwise known as the Children's NSF) was published in 2004. It differs from other NSFs in that it considers a young person from a multi-agency perspective and emphasis is placed on the working relationships and links with other agencies in social and educational services. CAMHS was included in the NSF and standard nine states that:

"All children and young people, from birth to their eighteenth birthday, who have mental health problems and disorders [should] have access to timely, integrated, high quality, multidisciplinary mental health services to ensure effective assessment, treatment and support, for them and their families." (Standard nine in the Children's NSF)

Recommendations accompanying this standard explicitly describe how a more equitable CAMHS could be developed and emphasise the importance of:

- Improving access by providing flexible arrangements *'…to take services closer to the young person's home'* (standard 9: 6.1).
- Improving emergency access to services in tier 4 (including IP CAMHS) (standard 9: 6.12).
- Improving service equity for vulnerable groups known to slip through service gaps, particularly:
  - Young people with mental health problems and a learning disability or pervasive developmental disorder (standard 9: 7.1).
  - Young people aged 16 and 17 years, with a recommendation to extend the age-range of CAMHS up to a young person's 18th birthday. In line with the National Service Framework for Mental Health (Department of Health, 1999) the standard also called for the establishment of clear protocols between CAMHS and adult mental health services to ensure a smooth transition from CAMHS to adult MH services.
- Improving arrangements for *'partnership working'* with other agencies that work with children with severe and complex mental health problems.

A 1.2.3 Policy implementation: support systems

A number of actions were taken centrally to support the implementation of Government policy in relation to CAMHS:

1. The National Institute for Health and Clinical Excellence (NICE) for England and Wales was established in 1999 to improve care through the use of evidence-based guidelines. Since then NICE have published five guidelines on mental health disorders that affect young people: Eating Disorders, 2004; Self-Harm 2004; Post-Traumatic Stress Disorder 2005; Depression in Children 2005; Obsessive-Compulsive Disorder 2005; Bipolar disorder, 2006. Some guidelines go further than informing the evidence base for treatments and practice, and make recommendations for the level of provision required to meet the needs of specified diagnostic groups. For example the 'Depression in Children' (2005) guideline refers to the Health Advisory Service four-tier model (HAS, 1995), which was adapted to present a stepped-care model of intervention that young people and their families should expect from the point of identification and assessment of need, through to the provision of an appropriate intervention (NICE 'Depression in Children' page 136). Central performance management requires NHS Trusts to show progress towards the implementation of NICE guidance (Department of Health, 2004a & 2006). This includes the Healthcare Commission's new annual review process which will measure how well trusts are doing in meeting guideline recommendations. This is further supported by the recent report on the implementation of the standard 9 of the Children's NSF which recommends that planners for CAMHS "offer a co-ordinated response to the totality of NICE guidance" (Department of Health and the Department for Education and Skills, 2006 page 7).

2. The Care Standards Improvement Partnership (CSIP), which was part of the National Institute for Mental Health in England (NIMHE) was established to support the implementation of mental health policy at a local and national level. The National CAMHS Support Service, which was part of CSIP, had regional development to support CAMHS work with local services and to help staff put policy into practice. In the West Midlands, the regional development worker was instrumental in increasing IP CAMHS provision by planning for a new acute IP CAMHS unit for adolescents (West Midlands Region CAMHS Services Steering Group, 2002). This was in part developed in anticipation of the Children's NSF and the need to improve access to emergency acute CAMHS care.

3. Monitoring systems: The CAMHS mapping exercise (www.dur.ac.uk/camhmapping) was established in 2001 to monitor and audit NHS CAMHS provision annually. The Healthcare Commission (HCC), with the support of the Mental Health Act Commission (MHAC) and NIHME, also monitor all hospital admissions for the treatment of mental illness including young people. A secondary function of the CAMHS mapping exercise and the Healthcare Commission is to assess whether the planned targets to increase provision by a minimum of 10% annually are met. With respect to bed provision, the CAMHS mapping data up to 2005 were limited in that they did not include beds provided by the Independent sector, which in 2006 now accounts for

36% of all CAMHS beds (O'Herlihy et al., 2007, see Appendix 4.2). A census by the HCC in March 2005 also provides important data on the use of adult mental health beds by young people.

While these targets are commendable, if they are to be met it is important that service planners know where the service gaps lie and for whom. In the next sections, brief consideration is given to the research context in which this study sits.

A 1.3 PREVALENCE AND HIGH RISK GROUPS

A 1.3.1 Prevalence of mental health problems among young people in the UK

In 1999 the Office of National Statistics (ONS) surveyed 10,438 children aged between 5 to 15 year olds. A third of this population was followed up at 20 months and 3 years to 'examine the persistence of disorder'. On the basis of this, the ONS estimated that 10% of children and young people in the UK have a clinical diagnosis for a mental disorder and 2% have more than one diagnosis (Green et al., 2004; Meltzer et al., 2000, 2003). This rate is consistent with a previous estimate by Rutter in 1976 and prevalence rates reported for Canada (Offord et al., 1992). Prevalence rates were found to be higher among boys for conduct and hyperkinetic disorders in comparison to girls aged 11 to 16 years (8.6 and 2.3% of boys compared with 3.8 and 0.5% of girls respectively). A comparison with data from the National Child Development and 1970 Birth Cohort Study suggests that, over a 25 year period, there has been an increase in the prevalence of conduct disorder, hyperactivity, and emotional disorders among young people (Collishaw et al., 2004).

The Children's NSF (Department of Health and Department of Education and Skills, 2004) estimated that in the UK there are 45,000 young people with severe mental health problems. In England, this represents 0.8% of all young people aged between 12 and 18 years. This age-group accounts for nine per cent of the total general population (49,138,587 based on the 2001 ONS census figures).

The ONS (2000) observed that in the UK the suicide rate among males aged 15 to 24 years has increased over the past three decades; from 10 per 100,000 population in 1974 to 16 in 2000 (ONS 2000); although a slight drop has been observed for those aged 15 to 44 years (Brook and Griffiths, 2003; Gunnell, Wehner and Frankel, 1999). The trend is much less marked in females aged 15 to 24 years over the same period; with only a slight change from 3.8 per 100,000 in 1974 to 4.4 in 2000. Equally an examination of the World Health Organisation (WHO) Mortality Database observed a rising trend in suicide rates for adolescents aged 15 to 19 years; with rates higher in males compared with females (10.5 vs 4.1 per 100,000) (Wasser, Cheng, and Jiang, 2005). The ONS survey also found that 28 per cent of 11-16 years olds with an emotional disorder reported self-harming behaviours and suicide attempts (Green et al., 2004).

A 1.3.2 High-risk groups within the adolescent population

Certain groups of young people are at a higher risk of experiencing mental health problems. These include young people who are 'looked after' by a local authority, the homeless, young offenders, and young people who misuse substances (Meltzer et al., 2000; Lader, Singleton and Meltzer, 2003). The ONS follow-up survey found that among young people with an emotional disorder 20 per cent had reported taking drugs compared to 8 per cent in the general population (Green et al., 2004). Current policy emphasises the need for commissioners and providers to ensure that services are available to these 'difficult to reach' young people (Department of Health and the Department for Education and Skills, 2006; Royal College of Paediatrics and Child Health, 2003).

A 1.3.3 Characteristics of young people who access IP CAMHS

A proportion of young people with severe mental health problems will require an intensive level of care away from their home and usual environment. In an ideal world, the important question for those who plan this element of service is what the extent of need is for inpatient care. In practice, however, demand for the service will not always be led by need. It is therefore important to start by examining the characteristics of those young people who actually get admitted.

Since the first adolescent psychiatric unit opened at the Maudsley Hospital in 1947 (Warren, 1952), a number of reports have described the characteristics of those who use IP CAMHS. Early reports used diagnoses and descriptions of behaviours that cannot easily be mapped onto today's diagnostic categorisations. These reports were often based on admissions to a single unit (Bruggen, Byng-Hall and Pitt-Aikens, 1973; Framrose, 1975; Steinberg, Galhenge and Robinson, 1981). A high percentage of young people admitted in the first few decades of inpatient CAMHS were diagnosed with personality disorder and had co-morbid substance misuse (Bruggen et al., 1973; Framrose, 1975). Clinicians have since asked why young people presenting with severe mental illness and diagnoses such as schizophrenia or major depression were generally absent from these earlier descriptions (Wrate et al., 1994). The admission practices of units at this time were also called into question and units were criticised for their 'selective' practices and varying treatment philosophies (HAS, 1986, para. 2.2.12).

Over the past decade or so, one national survey and two prospective multi-centre outcome studies (Jacobs et al., 2004; Wrate et al., 1994) have described the characteristics of young people admitted to modern IP CAMHS. The National Inpatient Child and Adolescent Psychiatry Study (NICAPS) (O'Herlihy et al., 2001; O'Herlihy et al., 2004) undertook a one-day census of all young people (aged 4 to 18) resident in all types of IP CAMHS in England and Wales on the 19th of October in 1999. This included general purpose units as well as specialist eating disorder, learning disability, psychiatric secure and forensic units. Wrate et al., (1994) studied 12 to 20 year olds admitted to four general purpose adolescent units over a three-year period from May 1986. The Children and Young People's Inpatient Evaluation Study (CHYPIE) was a more recent prospective outcome study that followed a cohort of young people admitted to four children's IP units and four general purpose adolescent IP units between January 2001 and March 2005.

Table A 1.1 summarises the results of these studies. To allow better comparison with the outcome studies, only the data relating to adolescents from NICAPS are

presented and this is done in two ways; firstly for those admitted to all types of CAMHS units and secondly, for those admitted to general psychiatric units.

In summary these three studies showed the following:

- Fewer males than females are admitted to IP CAMHS (males accounted for 36-43% in all three studies). When the eating disorder adolescent population were removed from the NICAPS data males accounted for 45%.
- NICAPS found that one third of females admitted had a primary diagnosis for an eating disorder.
- Apart from the eating disorder group, the majority of males and females were admitted for the treatment of a mood (affective) disorder and schizophrenia related disorders.
- 15% of the adolescents identified by NICAPS were from minority ethnic groups (this is compared to 10% of under 20 year olds in the UK).
- In comparison to community CAMHS populations, IP residents are a highly disadvantaged group in terms of their early life experiences, psychosocial disadvantage, and severity of their clinical condition (O'Herlihy et al., 2004; Wrate et al., 1994).
- Between 8 and 10% of adolescents admitted are in foster or institutional care. The ONS survey found that 37% of looked after children and young people (total in England 60,900) had a clinically significant conduct disorder, 12% had an emotional disorder and 7% had a diagnosis for hyperactivity.
- Among adolescents admitted to general purpose units in NICAPS, in terms of the HoNOSCA rating for alcohol or substance/solvent misuse 11.4% were reported to have moderate problems and for 4.4% these problems were severe.

Table A 1.1 Characteristics of young people who have accessed adolescent inpatient CAMHS units

Study	Method	Sample size	% of Males	Three main diagnosis	Outcomes and other factors
Wrate et al., (1994)	Cohort admitted to four general adolescent units over a three-year period	276 (12 to 20 years)	43%	ICD-9 (7 categories accounted for 90% of population) 1. Conduct disorder (n=56; 21%) 2. Neurotic disorder (n=40; 14%) 3. Adjustment disorder (n=38; 14%) 4. Emotional disorder (n=37; 14%) 5. Anorexia nervosa (n=31; 11%) 6. Schizophrenia (n=26; 9%) 7. Affective disorder (n=21; 7%)	• 34% were living with a step-parent and 8% were in institutional care (Wrate et al., 1994) • Compared to Swiss outpatient pop. the IP pop. showed a higher degree of psychosocial adversity, particularly for family discordance and communication. • Half of those with schizophrenia, affective disorders or adjustment disorders were admitted following a para-suicidal act.
O'Herlihy et al. (2001) – NICAPS	One-day census in October 1999 of all adolescents resident in all types of CAMHS units	469 (over 13 to 18 years)	36.5%	ICD-10 (3 categories accounted for 2/3s of population) 1. Eating disorder (n=104; 22%) 2. Schizophrenia, delusional and psychotic disorders (n=98; 21%) 3. Mood (affective) disorders (n=90; 19%)	Differences found between NICAPS pop. and the Audit Commission (1999) community CAMHS pop. for severity of problems with: • Hallucinations and delusions • Emotional and related symptoms • Self-care and independence
*NICAPS from dataset	One-day census in October 1999 of all adolescents resident in General CAMHS units	365 (aged 13 or over)	38.9% (45% if ED pop. removed)	ICD-10 (3 categories accounted for 2/3 of the population) 1. Mood (affective) disorders (n=93; 26%) 2. Schizophrenia, delusional and psychotic disorders (n=75; 21%) 3. Eating disorder (n=54; 15%)	• 38% were living with one parent (with or without partner) and 10% were in foster or institutional care and 2% were with other relatives. • 15% were from ethnic minority groups. • On HoNOSCA rating for alcohol or substance/ solvent misuse 11.2 had moderate and 4.4 had severe problems.
Jacobs et al. (2004) – CHYPIE	Cohort admitted to 4 general adolescent units	74 (aged 13 or over)	36.5%	ICD-10 (6 categories accounted for all of the population) 1. Affective disorders (n=34; 45.9%) 2. Eating disorder (n=14; 18.9%) 3. Schizophrenia and related disorders (n=8; 18.9%) 4. Anxiety disorders (n=5; 6.8%) 5. Conduct disorders incl. mixed (n=2; 2.7) 6. Pervasive developmental disorder (n=2; 2.7%)	• Positive gains were observed across a range of outcome measures; improvements were evident 12-months post discharge. • Benefits gained were associated with length of stay-longer admissions being more beneficial.

*Note: the remaining 30% are spread across 11 different diagnostic groups. In comparison to the other studies NICAPS found: Acute stress/adjustment disorders (n=26; 7%); Anxiety disorder (n=18; 5%); Conduct disorder (n=16; 4%); Personality disorder (n=9; 3%); Pervasive developmental disorders (n=6; 2%)

A 1.3.4 Benefits of receiving IP CAMHS treatment

The most recent UK study to examine the treatment benefits of IP CAMHS in four general adolescent and four general children's units found positive health gain at discharge and these benefits were sustained for up to a year post discharge (Jacobs et al., 2004). Positive change was observed in terms of their overall level of functioning as measured by the Child Global Assessment Scale (CGAS) ratings recorded at admission, discharge and 12-months post discharge. Similar to the findings of the systematic review undertaken by Pfeffier and Strzelecki (1990) and a later review by Kutash and Rivera (1996), Jacobs and colleagues (2004) found that the following factors predicted a positive health gain:

- Length of stay was reported to predict health gain with longer stays producing greater positive change;
- Therapeutic alliance between the young person, their family and the inpatient staff (involvement in treatment, positive expectations of treatment);
- Pre-morbid good family functioning.

Factors associated with poor outcome were high levels of aggressive behaviour which was associated with shorter length of stays (Green et al., 2007):

Due to ethical considerations randomised control trials that could test the benefits of IP care in comparison with other alternatives are not conducted in the UK. However, the international and UK literature provides support for the treatment benefits gained from residential psychiatric care in age-appropriate settings (Blanz and Schmidt, 2000; Green et al., 2007; Kutash and Rivera, 1996; Pfeffier and Strzelecki, 1990).

Although the evidence supports inpatient care as being an effective intervention, for some young people admission can be a frightening and bewildering experience that can disrupt family life, adversely affect social, education and occupational opportunities, and be perceived as stigmatizing and 'labelling' (Blanz & Schmidt, 2000; Green & Jones, 1998; Green, 2002; Jaffa & Stott, 1999).

A 1.3.5 Conclusion

Recent studies have provided valuable data on the characteristics of those who access IP CAMHS and the efficacy of these services. However, little is known about the demand for these beds and the characteristics of those who do not access IP CAMHS when referred.

The question of whether there are enough beds to meet the demand is central to establishing the policy targets outlined. In the next section a brief review of the beds available in IP CAMHS and models of service provision are presented along with reasons why there are concerns about service gaps.

A 1.4 PROVISION OF INPATIENT CAMHS AND MODELS OF CARE

This section describes i) current provision of CAMHS beds, ii) the models of IP CAMHS provision and, iii) evidence of gaps in this type of provision. Although the structure of CAMHS will be familiar to the reader to provide some context the tiered model for CAMHS is briefly described.

A 1.4.1 Structure of CAMHS in UK

The thematic review on CAMHS by HAS (1995) proposed a four-tiered model to assist future development plans. The model contains four tiers of provision from the point of identification at 'tier 1' through to the most intensive level of care at 'tier 4', where IP CAMHS are located. A young person should ideally be referred through each tier in succession according to their service needs to ensure an assessment of need is undertaken before being referred to the next level of specialisation. 'Tier 1' represents all the primary professionals a young person or their family could easily access informally, such as teachers, general practitioners, social services, and the voluntary sector. Access to 'Tier 2' then requires a referral from a tier one professional to a single member of a clinical team. 'Tier 3' represents multi-disciplinary outpatient teams who work with more complex problems, in which the 'tier 2' single professional is often located. It has been argued that tiers 2 and 3 should be provided within one service with a single point of entry (Royal College of Psychiatrists, 2005). The final upper 'tier 4' represents specialist inpatient, outpatient, and day-patient care (HAS, 1995) and referrals to these services should be routed through tier 3. The tiered model illustrates that inpatient units do not stand in isolation but are instead part of a system in which it provides a residential component (Maskey, 1998). CAMHS beds are a scarce and expensive resource and are generally provided on a regional basis, any examination of the demand for these beds within a defined population base must consider what services are available to the referring clinicians.

A 1.4.2 IP CAMHS bed availability in England

The first comprehensive count of all CAMHS beds (NHS and Independent sector) was undertaken in 1999 in the NICAP study (O'Herlihy et al., 2001). The findings reinforced previous reports of 'patchy' provision (HAS, 1986; 1995), and showed the inequity in provision across the regions in England and Wales.

To monitor changes in provision the NICAPS research team maintained a bed database and undertook two further counts. The first in 2003 was to inform the selection of areas for this study (see chapter 3 on methods under 3.3); the second in 2006 was to monitor changes over a period when providers were required to meet government targets to increase CAMHS provision (Department for Education and Skills, 2003). These are the most accurate data available because, although the CAMHS mapping exercise was underway by 2003, its data were limited to the NHS and did not include the Independent sector. Given that this provided 25% of all CAMHS beds in 1999 and that the NHS is the main purchaser of these beds (O'Herlihy et al., 2003), any picture of provision would be incomplete without their inclusion. For a fuller description of changes in provision from 1999 to 2006 readers can refer to Appendix 4.2.

A simple count of beds cannot address the question of whether there are enough beds to meet the demand, and what is considered to be enough is fraught with difficulties. However, there have been two recent attempts to do this; and this at least provides points of comparison with actual provision as counted by NICAPS. The Child and Adolescent Faculty at the Royal College of Psychiatrists' recommend that 20 to 40 CAMHS beds should be provided per one million in the general population (Royal College of Psychiatrists, 2005). This estimate was made after considering the ONS prevalence data, a CAMHS needs assessment by Kurtz, Thomas and Wolkind (1994), and the NICAPS bed data. At about the same time the Scottish Executive Child Health Support Group, after wide consultation, concluded that a total of 60 CAMHS beds were required for young people in Scotland: this is equivalent to 11.8 per one million of Scotland's total population of 5,078,400 (Scottish Executive, 2005). The discrepancy between the two recommendations may be due to the fact that in England a range of specialist and general units for children and adolescents are provided, whereas in the NHS in Scotland CAMHS beds are only provided for adolescents in general purpose units. This is the most common type of unit, and the term 'general' refers to units that accept young people with a wide range of diagnoses.

Table A 1.2 below shows the number of beds available per one million in the general populations across the English regions in 1999, 2003 and 2006. The regions which include the study strategic health authority (SHA) areas are highlighted in **bold italics**. While the majority of young people recruited to this study will be referred to units that only treat the adolescent age-group, a number may access beds in children's units (up to 14 years) and child and adolescent units (5 to 16 or 8 to 18 years). Therefore, to provide a complete picture and to allow for comparisons with the recommendations described above the table below present in columns:

    A. the number of beds in all types of CAMHS units and (beds in general purpose units only are in brackets) for the entire age group (4 to 18),

    B. the number of beds in all CAMHS units specifically for the adolescent age-group and (beds in general purpose <u>adolescent</u> units).

In 2003, 79% of all CAMHS beds were located in units for the adolescent age group (personal communication-O'Herlihy, 2003).

Table A 1.2: All CAMHS beds (beds in general purpose units) per one million in the total population. The shaded columns show the number of all CAMHS beds specifically for the adolescent age group (beds in general adolescent units) per one million.

[1]Regions	A Beds per 1 million in all types of CAMHS units for 4 to 18 year olds (Beds in general CAMHS units)			B Beds per 1 million in all types of CAMHS units for the <u>adolescent</u> age. (Beds in general purpose adolescent units only)		
	1999	2003	2006	1999	2003	2006
London	**26.5 (19.5)**	**43.1 (31.5)**	**44.2 (28.6)**	**21.1 (14.1)**	**[2]29.0 (25.1)**	**31.4 (23.6)**
North East	27.8 (11.9)	31.8 (13.1)	36.2 (12.7)	19.1 (8.0)	24.3 (9.1)	29.4 (9.5)
East Midlands	24.9 (9.7)	28.8 (7.3)	29.7 (10.2)	21.0 (5.8)	25.8 (4.4)	29.7 (10.2)
West Midlands	**10.4 (10.4)**	**25.8 (12.5)**	**25.8 (12.5)**	**8.5 (8.5)**	**23.9 (10.6)**	**23.9 (10.6)**
South East	23.2 (18.6)	23.5 (18.9)	25.5 (20.9)	19.1 (14.4)	20.7 (14.4)	22.5 (17.9)
South West	11.1 (8.1)	13.6 (13.0)	12.8 (10.5)	11.1 (8.1)	13.6 (13.0)	10.5 (10.5)
East	**11.9 (10.0)**	**12.2 (10.4)**	**12.6 (10.8)**	**10.0 (8.2)**	**10.4 (8.5)**	**10.8 (8.9)**
North West	**9.8 (8.3)**	**11.7 (10.2)**	**12.0 (10.5)**	**5.2 (3.7)**	**7.0 (5.5)**	**9.0 (7.5)**
Yorkshire and the Humber	11.3 (11.3)	10.9 (10.9)	9.1 (9.1)	8.9 (8.9)	8.3 (8.3)	7.9 (7.9)
ENGLAND	17.2 (12.6)	22.6 (15.3)	23.0 (15.0)	13.7 (9.3)	17.9 (11.8)	19.1 (12.7)

[1] English regions are based on boundaries set in 2003; the areas are ranked in order of the total beds per one million in 2003.

A 1.4.2.1 Inequitable provision across England

Table A 1.2 shows an inequity in IP CAMHS provision across England. The regions are sharply divided into five that exceed recommended bed numbers and four that fall well below. Also assuming Scotland's recommendation does refer to general purpose adolescent beds, then six out of the nine regions in England fall well below their recommendation for 12 beds. The inequity in provision was present in 1999 and, if anything, the gap became wider in 2003 and 2006 despite an overall increase of 34% (844 to 1128 beds) for all CAMHS beds, and 40% for beds in adolescent units (671 to 938 beds) (personal communication-O'Herlihy, 2006). This was because increases were greater in regions with high bed numbers in 1999 than in regions with low bed numbers (O'Herlihy et al., 2007 see Appendix 4.2). The only region to break the mould was the West Midlands where a strategic review of bed provision in 2002 led to the opening of one new NHS acute short-stay general adolescent unit and a 20-bed NHS forensic CAMHS unit, which was commissioned through the National Specialist Commissioning Advisory Group (NSCAG, 2005) (Corbett, 2002).

The information about bed numbers, derived from NICAPS, was used to select the population bases for this study in 2003. We selected SHAs from two regions with high bed provision (London and West Midlands) and two regions with low bed provision (East and North West).

A 1.4.2.2 Impact of the Independent sector provision

Between 1999 and 2003, there was a greater increase in the number of beds provided by the Independent sector than in NHS beds (personal communication-O'Herlihy, 2003). By 2003, the Independent sector managed 34% of all CAMHS beds and these were located in seven out of the nine regions; as opposed to five in 1999. Developments in the Independent sector are mainly driven by market forces as opposed to central planning or local need, and there is some evidence that this has contributed to the increasingly uneven distribution of beds across the country. Many of the Independent sector beds are used by patients funded by the NHS. It is therefore important that they are included in any study of inpatient provision.

At the end of this section table A 1.3a and A 1.3b provide a detailed overview of the type of beds available in the UK and the models of care during the study period.

A 1.4.3 Types of IP CAMHS units and models of care

The type of IP CAMHS available to young people can vary across regions. Table A 1.3a describes the different types of IP CAMHS available to young people in England.

Also in recent years, new models of tier four provision have been developed which supplement, or in some cases, act as alternatives to traditional forms of IP

CAMHS care. Table A 1.3b briefly outlines the models of care provided. These models illustrate the innovations that are currently being considered in CAMHS, and show how varied the level of provision may be between areas. Any examination of the demand for IP CAMHS beds must consider inpatient beds in the context of other local services at both tier 4 and tier 3.

Table A 1.3a Types of adolescent IP CAMH services and models of care

	TYPE	DESCRIPTION
1.0	**General adolescent unit**	This is the most common type of IP CAMHS, accounting for 52% of all CAMHS beds (1111 beds) in 2003. In 2003 the distribution of these units was uneven across England and six out of the nine regions fell well below Scotland's recommended number of 12 general adolescent beds per one million in the general population. These units admit a wide-range of diagnostic groups. Within this group there are two types of provision (in *italics* below):
1.1	*General adolescent medium-stay unit*	The majority of general units fall within this category and have an average length of stay of about 12 weeks (O'Herlihy et al., 2001; Jacobs et al., 2004). While most admissions to these units are planned, the models of care provided can vary and include all, some or none of the following: • Eating disorder beds with a separate treatment programme. The inequity described above means that some regions have no access to any specialist provision and the general adolescent unit is under pressure to meet the needs of a diverse group of patients. For young people who present with an eating disorder some general units now provide beds specifically for the treatment of this population (for example a proportion of their beds are ring-fenced and a separate treatment programme is provided). • Emergency provision: To improve access to emergency beds and provide acute/intensive psychiatric care for a short-period, some units dedicate a small number of beds to this level of intensive care. • Day- and out-patient care attached to inpatient units: A number of units incorporate day-, out-patient, or outreach services to provide a flexible model of care and facilitate continuity of care pre- and post admission. Day care places are offered on a full- or part-time basis with the option of an inpatient bed if the need arises.
1.2	*General adolescent acute (short-stay) units*	To meet the demand for emergency access an acute short-stay model of care was developed (Corrigall and Mitchell, 2002). These units are defined by a shorter length stay of 6 to 8 weeks and an acute more intensive level of care. In 1999 there was only one unit of this type but by 2003 a further three units with 36 beds opened, two of which were located next to the more common medium-stay units to ease transfer to a more appropriate level of care if the young person required inpatient care at a less intensive level for a longer period.
2.0	**Eating disorder units**	The majority are located in the South East and London with one Independent EDU in the West Midlands. NICAPS found that two thirds of young people with an eating disorder are treated in a specialist unit, while a third receive care in general CAMHS units (O'Herlihy et al., 2001).

	TYPE	DESCRIPTION
3.0	**Addiction and eating disorder unit:**	Only one 13-bed Independent sector unit opened between 1999 and 2003, but this unit had closed by the end of 2005.
4.0	**Secure forensic mental health service for young people**	These units provide medium secure care for young people with severe mental illness who are a danger to themselves or others, including those who have committed criminal offences. These are national beds commissioned through National Specialist Commissioning Advisory Group (NSCAG). Plans to increase provision to 8 units with 88 beds by 2008 are well underway (Department of Health, 2005 NSCAG report). By 2003 there were 48 beds in 3 units, which increased to 68 beds in 5 units in 2006 (O'Herlihy et al., 2007).
5.0	**Independent sector secure psychiatric units (low and medium secure)**	In 2003 these units were solely provided for by the Independent sector. Similar to the forensic unit they admit young people with severe mental illness who are at risk to themselves or others, but most do not admit young people who have committed serious criminal offences.
6.0	**Learning disability and mental health units**	In 2003 and 2006 a total of seven units provide mental health care for young people with a learning disability. One unit with 30 beds (18%) is provided by the Independent sector and two units (11 beds in 2003) are jointly funded by the NHS and social services. Of the remaining five NHS units, two provide care for younger children as well as adolescents.

Table A 1.3b: Models of care within tier-four CAMHS

	MODELS OF CARE:	
1.0	**Outreach teams**	Adolescent outreach teams have now been established in some areas, either attached to the unit or within the community. The team's primary purpose is to facilitate continuity of care and their activities include pre-admission assessment work, facilitating engagement with the young person and their family, linking in with other involved agencies, and the young person's local resources. Links are established with both NHS and Independent sector units.
2.0	**Behavioural Resource Centre**	In contrast to most of the services discussed so far, one CAMHS service, the Behavioural Resource Service in Southampton, has been jointly commissioned by health, education, and social services to provide crisis intervention and support for young people with complex mental health and behavioural difficulties. The service is primarily community based with the option of a short stay bed if required (four beds are managed within the service for adolescents). The impact this service has on other local services and, on meeting the mental health needs of the local population, is being evaluated as part of the Department of Health's CAMHS innovation projects evaluation programme (Kurtz and James, Department of Health, 2002).
3.0	**Home-based treatment programmes:**	Following on from the community based models established in adult mental health services, which were set up to reduce the need for hospitalisation and bring services closer to home, a similar model was developed and applied to CAMHS. The first programme was set up in Bradford and more recently a second programme has been established in Southampton. The effectiveness of these services and the impact on the use of other local services are being evaluated under the evaluation programme described above. The first evaluation of the Bradford service, based on six-months activity, is now available (Worrall-Davis and Kiernan, 2005).
4.0	**CAMHS liaison teams attached to adult wards:**	In line with the Children's NSF (Department of Health and Department of Education and Skills, 2004) recommendations, some areas have established CAMHS teams that are attached to designated beds on an adult ward. This is meant to act as short-term solution until more long-term solutions around provision are firmly in place.
5.0	**Early Onset Psychosis Teams:**	Policy requirements have set targets for the development of early intervention in psychosis (EIP) teams which provide care for young people as young as 14 years (upper age is 35 years) (Department of Health, 2000).

A 1.4.4 Further indicators of gaps in provision

A 1.4.4.1 Lack of emergency provision

Surveys of what referrers want from IP CAMHS units, irrespective of discipline, report a wish for improved access with prompt responses to emergencies (within 24 hours or a week) and shorter waiting times (Gowers, Symington, and Entwistle, 1991; Steinberg, Galhenge, and Robinson, 1981; Worrall and O'Herlihy, 2001). NICAPS confirmed the lack of emergency access; two-thirds of the units surveyed did not admit patients at short notice, or provide an admission service outside of office hours (O'Herlihy et al., 2003). Two later surveys in 2000 and 2005 by Cotgrove and colleagues indicate that units are adapting to the need to improve emergency access (Cotgrove et al., 2007). The number of general adolescent units with dedicated 'emergency admission beds' increased from 6 in 2000 to 16 in 2005 - out of a total of 79 IP CAMHS units surveyed. When units were asked about emergency admissions accepted, 46 out of 70 said they were able to admit within one day, but many estimated that only 24% of those in need would receive emergency access due to staff shortages, funding, and lack of bed availability (Cotgrove et al., 2007).

As mentioned above, the most common type of adolescent unit is general purpose which admits a wide range of diagnostic groups. As such they are under pressure to be all things to all people. Cotgrove (1997) described the impact these emergency beds had on the management and functioning of a general purpose unit and concluded that such beds should be managed in separate acute units. Corrigall and Mitchell (2002), who managed the first unit of this kind in England, proposed and discussed the benefits of providing acute (short-stay) IP care within CAMHS. The success of this model of care is shown by the fact that a number of NHS trusts have adopted it and there are now five additional acute short-stay units in England (O'Herlihy et al., 2007). All five are located next to a general purpose IP CAMHS to allow for easy transfer to a lower intensity of care and a longer length of stay if required; thereby maintaining emergency access to beds. Although these developments are encouraging, emergency beds are still not widely available across all units in England.

A 1.4.4.2 Admissions to other settings

Inappropriate admissions for MH treatment in other medical settings are a possible consequence of an uneven distribution of provision and poor emergency access to IP CAMHS (Gowers et al., 2001; Mental Health Act Commission, 2001 & 2004; Worrall et al., 2004). A sub-study within NICAPS estimated that about a third of all admissions of young people (under 18 years of age) for MH treatment were inappropriate placements on adult psychiatric and paediatric wards (Worrall et al., 2004). This appears to be a conservative estimate when compared to the findings from other surveys. Of most concern are the findings from a survey undertaken in a region of relatively poor bed provision. Gowers et al (2001) surveyed admissions, of 12 to 20 year olds with a discharge diagnosis for a psychiatric disorder, in two health authorities in the North West over a two-year period (1996-1998). They found that only 21 out of a total of 950 admissions were to a regional IP CAMHS unit. This study not only illustrated the extent of the problem in an area of poor bed provision but also showed the range of other IP services young people were accessing. The largest number of admissions

(n=355) were to adult MH services. All but 13 of such admission were aged 16 years or over. The majority of under 16s (186 of 225) were admitted to paediatric wards. Others were admitted to beds in adult medical wards and in some cases placed in accident and emergency departments where the 12-hour maximum trolley wait was breached (Gowers et al., 2001). The Mental Health Act Commission (MHAC) acknowledged this as an area of concern and surveyed both formal and informal admissions in 2003 to examine demand for CAMHS beds. However, the MHAC only looked at admissions to CAMHS and adult MH wards. Over an 18-month period, 270 notifications were received of young people detained under the act in adult MH services. However, 213 of these were reported for the last nine-months suggesting an under-reporting during the initial stages of the study when systems of collection were being established. The survey of informal admissions, reported by a third of all NHS trusts and quarter of Independent sector hospitals in the last nine months, identified 319 young people, 63% of whom were admitted to adult facilities compared to only 23% to inpatient CAMHS (MHAC, 2004). The MHAC concluded that these admissions were a direct result of a shortage of CAMHS beds and a lack of emergency provision.

Since the CIR study started, the Healthcare Commission has undertaken a survey of hospital residents in CAMHS, adult and old age MH wards. This provided some evidence that, despite an increase in CAMHS bed numbers, the problem was still there. A one-day census undertaken in 2005 found that 15% (n=338) of all under 17s year olds, who were inpatients on that day, were resident on an adult mental health ward (Healthcare Commission, 2005). The census did not include residents on paediatric wards and other settings, which may admit a substantial number of under 16s. In the North West where the bed provision has remained low since 1999 (O'Herlihy et al., 2007) the proportion of young people resident in adult settings remained high at 24% (Healthcare Commission, 2005).

Admissions to these settings are viewed to be inappropriate for young people with severe mental illness/disorders. Historically, concern about such placements of young people triggered the development of age-appropriate IP mental health care for adolescents (Cameron, 1949; Garralda, 1986; Parry Jones, 1995; Warren, 1952). The literature on adult psychiatric wards suggests that acute adult wards can be a disturbing environment in which to reside. Such wards often provide a poor experience of care for those admitted, with reported high levels of disturbance, incidence of assaults, and of patients feeling unsafe (Barker, 2000; MILMIS Project Group, 1995; Quirk and Lelliott, 2002; Scott, McGilloway and Donnelly, 2001; Worrall et al., 2004). Furthermore, adult wards often a) lack policies to protect young people's safety and interests, b) sometimes employ staff who have not been police vetted and c) have no access to education facilities (MHAC, 2004, page 18).

Admissions of young people to paediatric wards pose a different type of problem in that such patients can disrupt the treatment of younger children who present a very different range of behaviours and diagnoses (Wolkind and Gent, 1987).

A recent report from the Office of the Children's Commissioner (2007) is more specific about the poor quality of care that young people receive on adult mental health wards. The report identified four themes: i. 'a lack of involvement in care planning'; ii. 'lack of peer-support or having someone to talk to'; iii. 'lack of safety, security and therapeutic care'; iii. 'disorganised discharge arrangements'. These themes are the opposite of what young people report to be helpful about

receiving treatment in IP CAMHS unit. In this setting, young people greatly value the support from staff and peers, involvement in decision making and the sense of being safe (Hart, Saunders and Thomas H, 2005; Street and Svanberg, 2003).

A 1.4.4.3 Factors that might influence admission of young people to adult wards

Concern for older adolescents, and their displacement into adult inpatient services, is not new and was reported throughout the 80s and 90s (HAS 1986; 1995). The absence of emergency beds in CAMHS is probably the most immediate factor that accounts for inappropriate admission to an adult ward. However, there are other factors at play.

Although it is national policy that CAMHS should provide care up to the age of 18 years (Department of Health, 2004), this is interpreted differently across the country. Conditions are sometimes attached to the admission of those over 16, such as being in full-time education or having a definite home base or accommodation (Corbett, 2004). Funding disputes are known to arise when social services are reluctant to fund accommodation if a young person is approaching an age of independence, or while a young person is resident in IP CAMHS. Conversely the IP CAMHS unit will not accept a young person unless they have accommodation outside the unit to which they can return after discharge, or go on weekend leave (personal communication with inpatient and community CAMHS teams). Age limit discrepancies among other agencies such as education, social services and adult mental health services can also affect access to services and continuity of care.

The MHAC described the characteristics of young people admitted to adult wards. The majority of young people detained under the Act in adult MH wards were aged 16 and over (n=128). Males accounted for two thirds of the population and black and minority ethnic groups were over-represented compared to admissions to CAMHS and the child census population data (see MHAC, 2004 page 22). Those detained differed from young people who were admitted informally to adult MH wards. Females accounted for 51.5% of the latter group and the representation of black and ethnic minorities were similar to the child census population.

A 1.4.5 International perspective

In the US and Australia, the age limits for admission to CAMHS and adult wards overlap (CAMHS up to 19 years and adult MH 16 to 65). This allows for a more flexible choice about what service would best suit the young person's developmental status and maturity. If the problems relating to staff, policies, and education, identified by MHAC were addressed, this may be an option to consider in this country for some older adolescents.

The upper age limit for CAMHS has been a topic of discussion in Australia. Some have proposed the development of 'youth' mental services that would span the age range from adolescents as young as 12 through to young adults aged 25 years (McGorry, 1996). Others have questioned the wisdom of managing such a large age range and propose that young adults should be managed within specialist adult mental health services (AMHS) for 18 to 25 year olds with strong established links to both CAMHS and AMHS (Birleson, Luk & Mileshkin, 2001).

This is yet to be debated fully in the UK. As a short-term measure, however, the Children's NSF (Department of Health and Department of Education and Skills, 2004) proposed the establishment of CAMHS liaison teams to ensure the needs of this group were met during their stay on an adult mental health ward. More recently the report on the Implementation of standard 9 of the Children's NSF (Department of Health and Department for Education and Skills, 2006) stated that progress is to be made towards the elimination of the use of adult wards "for all but a few older adolescents who identify more readily with younger adults" (Department of Health and Department for Education and Skills, 2006 page 6).

In some countries CAMHS have been a part of the more general movement in mental healthcare towards community-based interventions, with minimum use of inpatient services. In the US the view that inpatient care is 'restrictive' and should be avoided has led to a shift away from long-term therapeutic care to short-term crisis intervention and evaluation (Green and Jacobs, 1998). For publicly funded care, referrals for hospitalisation are filtered through emergency mental health centres, which in some areas cater for all those over the age of 12 (Hillard, Slomowitz, and Deddens, 1988). Their role is to provide crisis intervention on demand and link in with the young person's community services. Admission to a hospital is only undertaken for reasons of safety and for treatment of an acutely ill young person. This new system of care strives towards providing care in the least restrictive way by not removing the young person from their home or community (Stroul and Friedman, 1986). The 'continuum of care' model in the US replaces the more traditional model of out-patient and inpatient services with intermediate levels of locally based intensive care, such as home-based treatments (Bickman et al., 1995). One such model reported by Sowers, Pumariega, et al., (2003) has six levels of care of increasing intensity:
- Community health management;
- Outpatient services;
- Intensive out-patient treatment;
- Intensive integrated service that does not require 24-hour psychiatric monitoring;
- Non secure 24-hour psychiatric care;
- Secure 24-hour psychiatric care.

The policy of the German Government, in response to concern about inequity of provision, is to provide the same type of services for young people with mental health needs as is provided for other disorders (Goodyer, 1998). Community and inpatient services are provided locally. The aim was to reduce time spent in residential care and to increase the opportunity of intensive community-based care with the option of an inpatient bed if required (Goodyer, 1998). While at first, the locally based inpatient service did appear to reduce the rate of referrals and admissions, an increase followed once services became more established and referrers adjusted to making better use of the inpatient service available to them (Goodyer, 1998).

While there have been shifts towards an ideology that inpatient care is best avoided, no country has yet managed to provide mental health care without any inpatient provision. By increasing the thresholds and shortening the length of stay, the benefits gained by an admission may also be lost. As discussed under section A 1.3.4 the findings drawn from systematic reviews and the CHYPIE study in the UK showed that the benefits gained from IP CAMHS treatment were

associated with longer length-of-stays (Jacobs et al., 2004; Kutash and Rivera, 1996; Pfeffier and Strzelecki, 1990).

A 1.4.6 Conclusion

The inadequacy of provision, while consistently reported over the last 50 years, remains evident. The variation in the number and type of beds available across the country coupled with the variation in age groups accepted for treatment within CAMHS, adult psychiatric services and other agencies, leaves some young people vulnerable to not accessing appropriate care when required. There does appear, however, to be a commitment by government to *'redress'* this inequity (Department of Health, 2001, Department of Health, 2004; Department of Health and Department for Education and Skills, 2006). What is not known, however, is the impact this inequity has on young people's use and access to IP CAMHS.

A 1.5 ACCESS TO INPATIENT CAMHS

The focus of this study is on whether adolescents that would benefit from admission are denied access to a bed. It is possible that a young person might be denied admission because the bed is occupied by another person who could have been treated as well, but less expensively, in a non-inpatient setting. It is important, therefore to consider the question of the optimal use of the IP CAMHS. In an ideal world, this resource would be used by those young people with the greatest need and the greatest potential to benefit (Cotgrove, 2001; Green 2002; Maskey, 1998). Access would be uniform across the country. If this was ever the case, it is possible that some young people who would benefit would still be denied admission due to scarcity of beds. However, such rationing could be justified on the grounds that those who were filling the beds were all in greater need. Recent descriptions of IP CAMHS populations show that, as a group, those using IP CAMHS have more severe and complex clinical and psychosocial problems than those using community CAMHS (O'Herlihy et al., 2004; Wrate, et al., 1994). However, this tells us nothing about the extent to which decisions about individual referrals or admissions are made consistently or about the extent to which beds are used optimally.

At the heart of the question of optimal use of IP CAMHS is the issue of what defines an appropriate admission to IP CAMHS. In practice, admission decisions are influenced by organisational and service-level factors, as well as by patient-level factors. This will always be the case in the real world. There might also be a third factor that influences decisions to admit that relates to the nature of the "market" for inpatient care in which supply of IP CAMHS outstrips demand for admission. Because, unlike on adult acute admission wards, admission decisions to IP CAMHS are made by those managing the supply, the attitudes and preferences of those making assessments are also likely to affect the final decision. The incentive systems that affect these decisions might operate differently in the NHS and the Independent sector.

One objective of this study is to identify what factors define a need for admission. Thus, although, in the real world, there is a complex interplay between patient-level factors and organisational and service-level factors, it is important to start by considering the two separately for the purposes of this

research. We start by providing a brief overview of the referral process, followed by a review of the literature about patient-level factors that determine that a young person needs, or will benefit from, admission. We then introduce the organisational and service-level factors that sometimes modify these decisions.

A 1.5.1 Referral routes to IP CAMHS

The CAMHS tiered structure suggests that referrals to IP CAMHS are only made after outpatient CAMHS options have been exhausted (Maskey, 1998). This is true for the majority of referrals, however, NICAPS observed that a substantial proportion (31%) were referred from a wide range of services and professionals (general practitioners, paediatricians, social services, adult psychiatrists, educational services, self/parent or guardian, accident and emergency departments, youth justice system) (O'Herlihy et al., 2001). The tiered model for CAMHS assumes that professionals at tier 1, such as GP, education, social services, the courts, and voluntary sector, are the first point of contact. For many young people it is often an adult, who feels there is something wrong or has concerns about a young person's mental health, who will initiate contact with services. This, however, may not apply to some older adolescents who sometimes present with more adult type disorders for example an acute psychotic episode and their first contact with health could be at an accident and emergency department when they are acutely ill. This factor combined with the disparity between CAMHS and adult psychiatric services about who takes responsibility for those aged 16 or over, may contribute to the difficulties this group face in accessing IP CAMHS.

A 1.5.2 Decision making in the context of UK referral and admission processes

The process of referral and admission will vary according to the type of unit to which the referral is made (general adolescent unit, specialist eating disorder unit, secure or forensic unit etc) and the services offered by that unit (for example, some general medium stay units also provide acute short stay beds and day-patient places). Excellent descriptions of the referral and admission process are provided by Bruggen et al., (1973), Cotgrove, (2001), Maskey, (1998), and more recently in the 'Depression in Children' NICE Guideline (NICE, 2005). For the purpose of this review the following points have been noted:

- Although enquires will be accepted from all professional agencies, many units stipulate that a consultant child and adolescent psychiatrist should be involved if a formal referral is to be made. This is to ensure that a full assessment has been carried out and that all outpatient options have been considered prior to referral.

- A referral can take the form of a request for: an emergency admission (within 24 hours or sometimes the next working day), assessment that requires an inpatient episode, or an assessment and planned admission for treatment.

- The decision to admit a young person to an IP CAMHS unit is complex and involves negotiations between the referrer, young person and their family, and the admitting unit. The final decision to offer a place, however, is made by the staff of the admitting unit. This aspect of the admission

process is specific to CAMHS and differs from how admissions to adult psychiatric wards are arranged.

- Contra-indications to admission such as disruption to the family and the young person's relationships, removal from their own school and social environment, the possibility of stigma and the potential to create dependency on the staff and the institution, are always considered (Dalton, Muller, and Forman, 1989; Gowers and Cotgrove, 2003; NICE, 2005).

- If a young person or their family refuse to engage and the young person poses significant risk of harm to themselves or others, clinicians can turn to the law to enforce a compulsory admission under a section of the Mental Health Act or in some cases the Children Act, although this is less likely (Mears et al., 2001). The CHYPIE study found that delays in admission or non-admissions sometimes increased the likelihood of a compulsory admission to hospital via coercive force or police (Jacobs et al., 2004).

Decision theory relates to the constructs used to describe how a decision was reached, by considering all the options available and the outcomes likely to be achieved by choosing any of those options (Resnik, 1987). Obviously, the goal is to select the best option available given the needs of the individual. However when resources are limited and varied, as is the case for inpatient CAMHS, the best option is not always available or accessible when a young person is in need of an immediate intensive intervention. If a comprehensive CAMHS is to be provided on an equitable basis for all those in need, then agreement about who is appropriate for this intensive level of care is required across services.

A 1.5.3 Patient-level and support factors

Reports about admission criteria in the UK are mainly descriptive and are based on clinicians' experiences and, with the exception of one multi-site study (Wrate and colleagues, 1994), describe the admission practice of single units (Ainsworth, 1984; Jaffa and Dezsery, 1989; Steinberg et al., 1981; Wells, 1989).

A 1.5.3.1.Characteristics of the young person and their mental disorder

One of the first studies in the UK to address the limitations of retrospective single unit designs was undertaken by Wrate et al., (1994). Over a three-year period the admission process was examined for a cohort of 276 young people admitted to four general adolescent units. The following reasons were reported in order of frequency from an examination of the reasons the units gave for each admission:

- *To provide a detailed psychiatric assessment (51%)*
- *To establish better therapeutic control (36%)*
- *To provide a therapeutic peer group experience (36%)*
- *To obtain improved control over the adolescent's behaviour (26%)*
- *To relieve outpatient colleagues from a treatment failure (20%)*
- *To assess or facilitate future placement needs (19%)*
- *To provide relief to exhausted parents (18%)*
- *To achieve psychological separation between the parents and the patient (17%)*

Although risk was not specified as a reason for admission the authors reported that over half of those with a primary diagnosis for schizophrenia, affective disorders and adjustment disorders were admitted following a para-suicidal act. The presence of risk alongside the need for intensive assessment and treatment are reported, by experts, to be the main categories under which criteria for admission fall (Cotgrove, 2001; Cotgrove and Gowers, 1999; Green, 2002). One recent example is the Depression in Children Clinical Guideline (NICE, 2005 page 147) recommendation about when a referral to tier 4 CAMHS is appropriate for young people with severe depression:

- *High recurrent risk of acts of self-harm or suicide.*

- *Significant, ongoing self-neglect (for example, poor personal hygiene, or significant reduction in eating that could be harmful to the physical health of the child or young person).*

- *Requirement for intensity of assessment or treatment and / or high level of supervision that is not available in tiers 2 or 3.*

There has been some debate about the primacy of diagnosis in influencing admission decisions. There does, however, seem to be broad consensus that, if other criteria are met, admission can be made for the purpose of assessment before a diagnosis of a mental disorder has been established. Thus although guidelines, recently developed by the Scottish Executive (http://www.scotland.gov.uk/publications/2005), state that there must be a mental disorder and/or presence of a severe ICD-10 diagnosis in relation to other factors such as risk if *"significant harm may ensue if admission does not take place",* they do allow for admission for assessment. This illustrates the complexity of decision-making in CAMHS. Clinical diagnosis may not always be known at the time of referral, and some contend that one of the main functions of an IP CAMHS unit is to clarify diagnosis in a 'controlled environment' (Green, 2002; Wrate et al., 1994). Others have challenged this and argue that inpatient CAMHS offers a false environment and that an assessment and diagnosis in most cases is better undertaken in the community where the young person is presenting their problems (personal communication with CAMHS consultants).

A 1.5.3.2 Support factors or aspects of the young person's circumstances that influence the decision to admit

In addition to patient-level factors many of the UK descriptive studies report that the need for assessment or treatment must combine with factors such as:
- When treatment cannot be resolved or managed with out-patient treatment alone (Gowers and Cotgrove, 1999; Wrate et al*., 1994*).
- Ability of the family to cope (Hersov, 1994; Warren, 1952; Wolkind and Gent, 1987; Wrate et al*., 1994*)
- Willingness to engage in treatment and motivation for change from the young person and sometimes the family (Cotgrove, 2001; Ainsworth, 1984).

The decision making process is complex and a clinician must refer to the presence or absence of a number of factors that contribute to their decision to refer and/or admit. The need for safety and treatment are often weighed against the contra-indications, mentioned above under A.1.5.3 (Dalton, Muller, and

Forman, 1989; Gowers and Cotgrove, 2003; NICE, 2005), to form the following questions:

Positive
- Will the young person benefit actively from such care?

Negative
- Will admission disrupt the young person's family relationships?
- Will removal from school and social environment create stigma?
- Will admission create dependency on the staff and the institution?
- Will admission result in the young person acquiring more symptoms or worsening of symptoms (e.g. self-harm) or behaviour reinforced such as 'contagion' among eating disorder patients?

Preventative
- Will admission reduce the likelihood of suicide?

A 1.5.3 3 How patient-level factors combine

In a review on CAMHS admission practices, Maskey (1998) concluded that there are *"no absolute indications for IP care...rather there are combinations of factors that determine referrals and admissions".* The Wrate et al., (1994) multi-site study of admissions to four general IP CAMHS identified four reasons for admission of those with a diagnosis for a conduct disorder or emotional disorder but only two for young people with a primary diagnosis for schizophrenia, affective disorders and adjustment disorders. Contrary to the mostly descriptive research in the UK, empirical methods have been employed in the US to examine how factors combine to predict hospitalisation. Suicidal tendencies are reported to be the strongest predictor but only in combination with other factors such as substance misuse or assaultive behaviour (Gutterman et al., 1993), presence of a primary diagnosis of schizophrenia and symptoms of delusions, paranoia (Bickman, Foster and Lambert, 1996), or for affective disorder (Hillard et al., 1988).

The above studies identified a) factors that predict hospitalisation and b) how factors combine to predict hospitalisation prior to admission. What factors clinicians consider when making their decisions about who to admit had not been explored empirically. To address this paucity in the US, Morrissey and colleagues (1995) devised a method to investigate the combination of criteria clinicians use to determine who is appropriate for hospitalisation among a population of suicidal adolescents. From the available literature they identified six-criteria that were frequently associated with suicidal risk. A questionnaire was then developed that contained a generic base vignette followed by separate vignettes which were presented in list-form describing the presence or absence of each of the six-criteria. They purposefully chose this list format to ease the speed of completion and so as not to 'challenge' the reader to extract the information from the vignette.

Before this can be undertaken in the UK, it is necessary to first obtain a measure of consensus among clinicians on what they consider important to their decisions to refer and admit. Although there appears to be consensus among experts for three or four factors, a wider range of factors are reported in the literature particularly clinical factors alongside other support factors such as the family's ability to cope. Once agreed and operationally defined the ability of these criteria to judge 'appropriateness' for admission can be tested. As a first step this study reviewed the literature in this area to identify all relevant factors

reported in more than one study. The findings from the review are summarised in table A 1.4 below.

Table A 1.4 Clinical and support factors reported to determine admission to inpatient CAMHS in the UK and the US.

ADMISSION CRITERIA REPORTED IN THE CAMHS LITERATURE	Literature references & comments
A. PRESENCE OF SEVERE AND DEBILITATING MENTAL ILLNESS	**Main determinant in adult MH literature** **UK: Scottish Exec. Child Support Group (2005); Jaffa and Dezery, (1989)**
1. Primary diagnosis of schizophrenia and symptoms of delusions, paranoia or primary diagnosis of affective disorder	US: Bickman et al. (1996)-US: only predictor in traditional model of care group (standard outpatient and inpatient care); Hillard et al. (1988)-affective disorder for adolescents.
2. Higher internalising scores in P-CGAS or level of functioning	US: Bickman et al. (1996) when intermediate care options between OP and IP were available. UK: CHYPIE (2004); NICAPS (2001); CHYPIE found that CGAS scores on admission ranged from 35 to 55.
B. RISK AND PLACE OF SAFETY	**Main determinant in adult MH literature**
4. Need for emergency safe place if at risk to themselves / significant risk of suicide or self-harm	UK: Cotgrove (2001)-review; Garralda, (1986)-review specific to children's services; Jaffa and Dezery, (1989)-survey of referrals to CAMHS unit; NICE Depression in Children Clinical Guideline (2005); Scottish Exec. Child Support Group (2005); Steinberg et al., (1981)-cohort study of adolescents admitted to single unit. US: Bickman et al., (1996); Gutterman et al., (1993); Hillard et al., (1988);
5. Number of suicidal attempts/nature of previous attempts	US: Dicker et al., (1997); Hillard et al., (1988).
6. History of sexual abuse	US: Hillard et al., (1988)-2nd strongest predictor with primary diagnosis of affective disorder.
7. Substance misuse problem	UK: Jaffa and Dezery, (1989). US: Gutterman et al., (1993).
8. Risk to others	UK: Jaffa and Dezery, (1989); Steinberg et al., (1981). US: Costello et al., (1991)-children (2 to 12 years); Gutterman et al., (1993).
9. Aggressive outbursts in the	UK: Jaffa and Dezery, (1989); Steinberg et al., (1981);

	context of illness	US: Costello et al., (1991)-children (2 to 12 years).
C. NEED FOR INTENSIVE PSYCHIATRIC ASSESSMENT		
10	Formulation of the problem is unclear / puzzling presentation / difficulty in reaching a diagnosis due to complexity of the case	UK: Cotgrove (2001); Green (2002)-review; Scottish Exec. Child Support Group (2005); Wrate et al. (1994). US: Costello et al., (1991)-children.
11	To take place away from the family or usual environment if of benefit to the young person	UK: Cotgrove (2001); Garralda, (1986)-children; Green (2002)-review; Scottish Exec. Child Support Group (2005); Wrate et al. (1994); Wolkind and Gent, (1987).
12	Assessment to inform case management and future care needs	UK: Cotgrove (2001); Scottish Exec. Child Support Group (2005); Steinberg et al., (1981).
D. NEED FOR INTENSIVE PSYCHIATRIC TREATMENT		**UK: Green (2002)-review; Cotgrove (2001); Wrate et al. (1994).**
13	Therapeutic peer-group experience	UK: Wrate et al. (1994).
14	Control over the YP's behaviour	UK: Wrate et al. (1994); Steinberg et al., (1981). US: Costello et al., (1991)-children.
15	Treatment complications, not responding to treatment or condition worsening despite adequate out-patient treatment/ openess to outpatient treatment (Dicker et al., 1997)	UK: Garralda, (1986)-children; Gowers and Cotgrove, (1999)-review; Green (2002)-review; Wrate et al. (1994); Jaffa and Dezery, (1989); Wolkind and Gent, (1987). US: Dicker et al., (1997).
16	Psychological separation from parents or family	UK: Green (2002); Wrate et al. (1994)-the reason units gave for admitting 17% of the cohort. US: Costello et al., (1991)-children.

E. OTHER FACTORS FALLING OUTSIDE THE MAIN DOMAINS		
17	Provide relief to exhausted parents no longer able to support or manage / family response to attempted suicide (Dicker et al., 1997).	UK: Hersov (1994); Wolkind and Gent (1987); Wrate et al., (1994). US: Bickman et al. (1996); Costello et al., (1991)-children; Dicker et al., (1997).
18	Willingness to engage in treatment	UK: Ainsworth (1984); Cotgrove (2001).
19	Adequacy of social supports/peer relationships (Dicker et al., 1997)	UK: Ainsworth (1984); Cotgrove (2001). US: Dicker et al. (1997).

A 1.5.5 Organisational and service level factors that influence admission decisions

Given the inequity in provision, service and organisational factors are likely to influence referral and admission decisions. This has been shown to be true in the US where admission thresholds were found to differ according to the level of resources available (Bickman et al., 1996). Furthermore, many of the single unit studies emphasised the need to consider the impact of an admission on a unit's current capacity (staff skill mix; nurse to patient ratios) and the dependency levels of other young people on the unit (Steinberg et al., 1981; Wells et al., 1989). Some have warned that the failure to consider these service factors could lead to the collapse of the therapeutic programme (Steinberg et al., 1981).

In this country, the uneven distribution of provision and poor emergency access are factors that partly explain why some adolescents with mental health problems are admitted for treatment to settings other than IP CAMHS (Gowers et al., 2001; Mental Health Act Commission, 2001; 2004; Worrall et al., 2004).

A1.6 CARE PATHWAYS BEYOND THE POINT OF ENTRY

This study differs from other care pathway studies in that it aims to explore the care paths followed after access to inpatient CAMHS is denied or not taken up. This section briefly reviews the care path models proposed to inform research in this area, and concludes with a summary of the study's key aims and methods.

A 1.6.1 Care path models

The 'pathways to care' literature and the models proposed within, provide a theoretical framework from which to explore the factors that influence access to mental health services. Although the focus of most models has been on service use and help-seeking behaviours prior to first contact or initial stages of treatment, the concept of 'pathways to care' offers a way of exploring the use of health resources. One of the most cited models, the Goldberg and Huxley's (1980) filter model provides a framework for how individuals reach and move through mental health services. The model assumes that individuals, prompted by a desire to alleviate distress, move through a series of levels from community, primary care, through to secondary and tertiary health care. While acknowledging the contribution made by this model others have criticised its narrow and linear focus and argue that *'routes by which people arrive at their destination may be more varied and delays more extensive than the Goldberg and Huxley model acknowledges'* (see review by Lincoln and McGorry, 1995).

This is particularly true of the routes taken through CAMHS, which are varied and not always routed through the health service categories of primary, secondary and tertiary services (see the four-tiered model for CAMHS – HAS, 1995; Royal College of Psychiatrists, 2005). Beyond the broad base of tier 1 CAMHS, referrals to specialist inpatient services are not always filtered through the CAMHS structure but can come directly from other agencies (social services, education, youth justice system) as well as health (CAMHS professionals in the community, general practitioners (GPs), paediatricians, adult psychiatrists) (O'Herlihy et al., 2001). The model also assumes that as soon as an individual or carer wishes to seek-help and act on that wish, that the necessary services are available and accessible or that the individual is the one who controls the decision. The inequitable distribution of CAMHS beds across the country and the results from NICAPS and surveys of admissions to adult and paediatric wards indicate that there are insufficient beds to meet the demand. Equally the decision to admit does not solely lie with the individual seeking help. For young people the routes to care and mode of contact (formal and informal) can be varied, and delays more extensive than the model suggests (Lincoln and McGorry, 1995). This was confirmed by an examination of the pre-admission pathways to IP CAMHS in the CHYPIE study (Jacobs et al., 2004). Significant delays were experienced prior to admission and parents reported that at every stage they viewed their child's problems as severe and found the referral to IP CAMHS helpful (Jacobs et al., 2004).

Although the model has been applied to CAMHS to quantify service use and identify how an individual moves through the care system (Gater et al., 1991; Gater and Goldberg, 1991; Kapil et al., 2002), the focus has been on the initial stages of treatment or first contact with services; rather than on the subsequent pathway. Lincoln and McGorry (1995) emphasise the need to examine care pathways beyond the 'gateway'. They suggest employing a model that can

consider the impact on the lives of those affected and how their future care paths are shaped. It is argued that the quantitative methods employed in psychiatric medical research should be combined with qualitative methods to encompass the wide range of influences that impact on an individual's service use (Lincoln and McGorry, 1995; Morgan et al., 2004). Models must account for the complexities and variations in an individual's care path and include the views and experiences of those affected as well as the professionals involved in providing care. Service level factors must also be considered.

The inequity in provision and the varied availability of other intensive levels of care in the community (day patient programmes, intensive outreach, early onset psychosis teams-see table A 1.3b) mean that the services required may not always be available. These factors need to be considered alongside the young person and/or parent's desire to seek help or engage with services. This study differs from other care path studies in that its primary focus is to examine the care young people receive following a non-admission to an inpatient CAMHS unit. For this purpose a combination of quantitative and qualitative methods are employed.

A 1.6.1.1 What methodological approach should be taken?

The review by Morgan et al., (2004) highlighted the polarisation that has existed between quantitative and qualitative methodologies in the study of 'pathways to care'. They critique the more deductive approach that is often employed in psychiatric medical research, where the tools of survey and epidemiological methods are utilised. It has been argued that while these methods produce quantitative data that contributes to the identification of socio-demographic characteristics, care pathway typologies and clinical profiles, the inference of casual relationships between one variable and another on the basis of statistical associations is insufficient and the true nature of these relationships remain unknown. They refer to the contribution made by sociological and anthropological studies where an inductive process has been employed through methods such as narrative interviews with those who are experiencing the 'pathways to care' under study. Through the use of this method 'pathways to care' has been conceptualised as a social process that encompasses the wide range of influences that could impact on an individual's beliefs, experiences and help-seeking actions (family and community networks). Morgan, et al. (2004) and Lincoln and McGorry (1995) both conclude that future research in this area should combine both methods.

A 1.6.1.2 Care path model beyond the gateway

A variety of models have combined quantitative and qualitative approaches to explain access and receipt of mental health services. Pescosolidio's (1991) Network Episode Model (NEM) illustrated how this can be done as it recognised the contribution of what she termed 'contingency' approaches on understanding patterns of contact and service use as well as profiling the population under study. To explain how, when, and why individuals come into contact with services, the model promotes 'process orientated' approaches, which recognise the influence of social processes on help-seeking behaviours and subsequent service use. The authors, however, revisited the model to include organisational factors and decision theory in recognition of how the structure and availability of services impact on referral decisions (Stiffman, Pescosolidio, and Cabassa, 2004). They proposed the 'Gateway Provider Model' to test how access is

determined by…*client need, and organisational context, providers' knowledge and perception* [with the] *inclusion of decision theory principles'* (Stiffman et al., 2004, page 195). This is particularly relevant to CAMHS in the UK where the provider (the admitting unit) often makes the final decision on whether or not to offer a place for admission (see previous section).

The impact a non-admission has on a young person, their family and on their future use of mental health services has not been studied. If we are to gain a meaningful understanding of what happens to this vulnerable group following non-admission, it is important that we also consider their views and experiences of the care paths they subsequently followed. The above reviews and models highlight the need to consider a number of perspectives when exploring the care paths of those in need of mental health services. If we are to understand the gaps and barriers to accessing appropriate services and learn how to address these gaps it is essential that we understand service user and parents' experiences of the care paths they have followed.

A 1.6.2 Views of young people and parents and clinicians

The importance of involving service users in the planning and development of services has been part of the government's agenda for the past twenty years (Department of Health Social Services Inspectorate, 1991). All policy documents relating to CAMHS now provide guidance and standards for young people and their carers' involvement in service planning, development and research (Department for Education and Skills, 2001; Department of Health 2001; 2002; 2003; Department of Health, 2004; Department of Health and Department for Education and Employment, 1996). The Royal College of Paediatrics and Child Health, (2003) emphasise that the '*views and needs of young people should be taken into account at all stages of planning and delivery of health services for adolescents'*.

With a population of young people, parent or carer interviews are particularly relevant as the main carer will often play a role in advocating on behalf of the young person. Many young people are also still living with their family or carers and a non-admission to a service will have an impact on not only the individual referred but also their carers. In Lincoln and McGorry's (1999) critical appraisal of the literature they illustrate how user and clinician perspectives may differ, with the family perspective providing yet another view point (Hatfield and Lefley, 1994).

The care path models described in the previous section highlight the importance of including the perspectives of the service providers and clinicians involved in providing care. The focus of this study is on the care paths followed by those who do not access IP CAMHS when referred. The referring clinician's decision to refer to a specialist service has an impact on the care the young person will access as will the providing service's decision to offer care. By identifying and understanding the positive and negative aspects of a young person's care pathway, service planners will be in position to address these issues in their plans to improve provision. A by-product of this insight could influence how these young people use and access services in the future and through their lifespan if required.

A 1.6.2.1 Use of qualitative methods in the study of care pathways

The views of those not admitted when referred to IP CAMHS have not been explored before. As a new area of exploration it is important that the methods employed aim to elicit the personal narratives and meaningful stories from those affected so that they can be encouraged to contribute to discussions on how services should be delivered to meet their needs (Lincoln and McGorry, 1995). In this study we plan to employ in-depth interviews to enrich our understanding of some of the care pathway patterns identified for those not admitted to IP CAMHS when referred. It is intended that these interviews will complement the findings that emerge from the quantitative mapping of the care pathways followed. The larger main study will provide numerical and descriptive data on the patterns of care pathways followed, by whom (characteristics of the population) and why (reason given for non-admission). This will be followed by the proposed in-depth interviews to capture the views and experiences of young people and their parents who followed some of the care pathway patterns identified from the quantitative study.

A 1.6.3 Conclusion

This study aims to explore the factors that influence the care paths subsequently followed by those who are refused an admission to inpatient CAMHS. In addition to the individual and their family, service level factors are likely to play more of a role in shaping the care pathway followed. Given the lack of capacity, and the desire to provide a comprehensive CAMHS it is important that the gaps in service provision are understood.

Other than what has already been described we know very little about this substantial number of young people and how they fare through the mental health system as a consequence of not being admitted when referred. If we are to understand the gaps in provision, and why and for whom they exist, service planners need to be informed about how to close these gaps and ensure equitable access for all those in need. Interviews with those who experience the care paths identified will inform how these gaps can be closed.

A 1.7 RESEARCH QUESTIONS AND STUDY OBJECTIVES

This study required a population-based design to examine the demand for CAMHS from defined geographical areas and the care paths followed by those adolescents referred for IP CAMHS but not admitted. Quantitative and qualitative methods were combined to understand how the care paths affected young people and their parents or carers, and what their experiences were of the care received.

The overall aim of the study is to further inform policy and service development plans for this specialist level of care by better understanding:

- The demand for adolescent CAMHS beds in areas of England with high and low provision of IP CAMHS;
- The reasons for admission and non-admission;
- The care paths followed by those not admitted;

- Young people and parents' experiences of the care paths followed;
- The clinical factors and service level factors that influence decisions to admit;
- The extent of consensus about criteria that constitute 'appropriateness' for admission.

This study builds on the NICAPS findings and previous reports showing gaps in IP CAMHS, specifically for the adolescent population (12 to 18 years) in England. The study aims to inform service planners about the characteristics of those not admitted, their contact with services post non-admission, and their views on the care received. Consensus for what criteria could determine admission are also obtained.

Note: Unfortunately due to the low response it was not possible to complete the qualitative component of the study and it is not reported further here.

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