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## Development of quality indicators for youth mental health in primary care

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**Development of quality indicators for youth  
mental health in primary care**

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**Submitted to the University of London for the degree of PhD**

## ABSTRACT

Quality indicators are becoming increasingly important in primary care service delivery but despite the focus on involving patients in health services research and service development there are few examples of youth participation in quality improvement for primary care mental health. Similarly, investigating youth views on help seeking has not been done by involving young people as co-researchers. This means that current quality assessment and the evidence on which policies regarding youth mental health in primary care are based may not fully represent experiences and needs of young people.

This study aims to understand young people's views on seeking help for mental health problems and the role of primary care and to develop a set of user-generated quality indicators for managing youth mental health problems in primary care. A secondary aim is to seek professionals views of the user-generated quality indicators. The overall objective of this study is to achieve these aims by involving young service users as co-researchers using a participatory research model.

Young service users were recruited and trained as focus group co-facilitators. Seven focus groups and three interviews were conducted with fifty participants aged 16-25 both with and without mental health problems. Each group was repeated to ensure respondent validation. Young service users developed quality indicators from the focus group and interview data and ranked each one in order of importance using nominal group technique. Young service users presented the quality indicators to primary care professionals (PCPs) through focus groups. Three interviews were also conducted with PCPs. A thematic analysis was conducted on the data from focus groups and interviews with young people and PCPs. Disagreements and alternative interpretations of both data sets were discussed amongst the coding team which included young service users, researchers and PCPs.

Young people considered it appropriate not to seek help and felt it involved an element of risk. Contrastingly, they also acknowledged that seeking help was useful. Forty-six quality indicators were developed and ranked by young service users. Agreement was defined as 100% of scores within a two-point region. Group consensus existed for sixteen quality indicators representing the following aspects of primary care: better advertising and information; mental health training; more treatment options; improved referral protocol; and interaction during consultation. Thematic analysis of the focus groups with PCPs resulted in the following themes; examination of skills, determining the accountability of primary care and the role of commissioning and incentives.

The thematic analysis of the focus groups and interviews with young people illustrates that this group both advocate and choose not to seek help. This adds to our understanding of

the role of primary care for youth mental health problems. The user-developed quality indicators were similar to existing quality improvement initiatives in the areas of advertising, confidentiality, mental health training and access to talking therapies. There were marked differences in the areas of treatment options, referral protocol, and interaction during consultation. The young user-developed quality indicators can enable patient views to have an impact on practice and policy although they may challenge professionals more than those developed with less service user involvement. In addition, further evaluation of the user-generated quality indicators is required to facilitate their implementation.

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## CHAPTER ONE: INTRODUCTION

Mental health problems are the second most likely cause of morbidity and mortality worldwide in young people aged 15-24 years (WHO, 2001). In England, Primary care has been asked to play a significant role in addressing this health concern (NICE 2005) and many commentators argue that primary care is well placed to serve the needs of young people with mental health problems (Haller et al. 2009; Kramer & Garralda 2000). Yet compared to other age groups, young people are least likely to seek help from primary care for their mental health problems (Oliver et al. 2005; Bebbington et al. 2000) and when they do they are unlikely to have their mental health problems identified (Haller et al. 2009). In addition, young people who are either homeless or from minority ethnic groups are even less likely to seek help from primary care for their mental health problems. Quite evidently therefore, many young people affected by mental health problems are not having their needs met by primary care.

One way of attempting to address patients' needs has been through the advent of patient and public involvement in research and service development. This has been the rhetoric of the present and immediate past governments and has been hailed as a way of committing to a democratic and patient-centred health service. Patient involvement is usually achieved through consultation, although there are also some examples of collaboration with health professionals and patient-controlled research. This thesis takes a critical view of the way that young patient perspectives are received within primary care. In the field of mental health young people are usually involved by consultation rather than collaborative/collaboration studies. This is one of the first studies to involve young people as co-researchers using a participatory research model in primary care mental health research. By using this methodology young service users were empowered to collaborate with researchers and primary care professionals (PCPs) through the research process which enabled them to have a meaningful impact upon both the process and results of this thesis.

Improving the quality of primary care has been the central aim of a series of improvement initiatives throughout the NHS over the last decade through the development and implementation of clinical guidance, national audits and the provision of incentives to GPs (Roland et al. 2004). Patient surveys have been used to monitor the quality of care received but have a limited impact upon service delivery so it would appear that a new method of incorporating patients' views into quality assessment is required.

Patient-reported outcome measures and quality indicators are to be increasingly used to inform practice and commissioning decisions (Department of Health 2010), but because

these are usually designed by health providers, they may well not ask the questions that patients consider important. Patients have been involved in the development of quality indicators for primary care mental health but none have reported specifically on the views of young people themselves (Shield et al. 2003). Quality improvement initiatives aimed at youth health and mental health services have not reported specifically on how or whether young people were involved in the development process. The first aim of this thesis is to develop a series of patient-generated quality indicators for youth mental health problems in primary care.

With regard to managing mental health problems GPs are concerned about resources and interface issues with specialist services (Chew-Graham et al 2002; Kadam et al. 2001). They also report the importance of a patient-centred approach in managing mental health problems in primary care (Sigel & Lieper 2004; Rogers et al. 2001). I have found no studies that asked PCPs about patient-generated quality indicators for youth mental health care. The second aim of this study is to investigate PCP views of the quality indicators.

Young people are often embarrassed about seeking help from GPs and are concerned about confidentiality (Booth et al. 2004; Jacobson et al. 2001). With regard to mental health problems specifically, they consider GPs to lack knowledge about mental health problems, that they are dismissive, and that GPs lack the ability to refer them to talking therapies (Biddle 2006). Adults have similar views but also question whether it is legitimate to consult a GP about mental health problems. Studies with adults report that some had positive experiences of feeling respected and listened to (Kadam et al. 2001) and young people value being referred (Biddle 2006; Leon 1999). These studies did not report whether young people with mental health problems were involved in the data collection and analysis of youth views about seeking help for a mental health problem. The final aim of this thesis therefore is to explore the views of young people from a wide range of backgrounds in collaboration with young service users as co-researchers about seeking help for mental health problems and the role of primary care.

## ***Study background***

This thesis was developed from a study funded by the London Research and Development Directorate in 2001. It was one of 11 studies funded with the explicit aim of increasing service user involvement in primary care research. These covered a wide range of topics including:

- Orthodontics.
- Learning disabilities.
- Child health surveillance.
- Communication difficulties.
- Mental health.
- (Screening for) tuberculosis.
- Falling.
- Self management.
- Unmet health needs.

The funders also provided training and support for the research teams so as to facilitate the involvement of service users in the research process (Barnard et al. 2005).

## ***Overview of the thesis***

In Chapter 2, I will outline epidemiological trends in youth mental health and the main issues affecting the management of mental health problems in primary care. Lay and professional views on managing mental health problems and the role of primary care will be reviewed to assess our understanding of the help seeking process from both perspectives. Quality improvement in primary care mental health will be defined and explored. I will present a review of patient involvement in primary care and mental health research with a focus on youth participation in healthcare research.

Chapter 3 describes and justifies the methods used:

- to generate the young service user-developed quality indicators,
- to investigate primary care professionals' views of the quality indicators and
- to explore young people's views of seeking help for mental health problems and the role of primary care in this process.

Central to this thesis is the use of a participatory research model with young service users. I will review the theoretical assumptions which have guided this methodological approach and describe the use of focus groups, interviews and nominal group technique to achieve the thesis aims.

Chapter 4 presents the results from the 3 studies within the thesis. The thematic analysis of the focus groups and interviews with young people found that young people felt it was appropriate not to seek help, and that help seeking was a 'risk', but also acknowledged that it served a purpose and was therefore 'functional'. The results of the pilot work and the sixteen quality indicators which met criteria for agreement by the young service users will be presented. Finally, the qualitative investigation into PCP views of the youth-developed quality indicators generated three global themes:

- the quality indicators brought about an examination of PCP skills;
- PCPs required the accountability of primary care to be determined; and
- implementation of the quality indicators required the consideration of top-down initiatives such as commissioning, incentives and clinical guidance.

Chapter 5 discusses these findings in relation to the evidence and illustrates how these findings differ from what is already known about quality indicators for youth primary care mental health, and PCP and youth views on seeking help for mental health problems. The implications for policy and practice are also explored.

Chapter 6 concludes the thesis by summarising the findings and implications of the research and makes recommendations for further work.

### **A note on terminology**

The Oxford English dictionary definitions of both 'youth' and 'adolescence' are more or less interchangeable, both referring to the 'period between childhood and adult age' (Oxford Dictionaries 2008). However, this is not mirrored in the literature. Historically, the terminology used in research studies has been guided by the way health services are structured. Child and Adolescent Mental Health Services (CAMHS) generally work with individuals aged between 5 and 18 years. As a result the literature about mental health problems in young people aged up to 18 years more often than not brackets them together as 'children and adolescents'. Within this group studies that focus on those aged 15 years and under usually refer to participants as children while the terms 'adolescent' and 'young people' are applied to participants aged over 15 years old. By contrast, the World Health Organisation defines adolescents as people aged 10-19 years, youths as 15-24 year olds, while young people are defined as being between 10 and 24 years old (WHO 1986). In recent studies age ranges between 10 and 19 years of age are now also included in studies about 'young people', and 'young adults' are generally defined as being those between 20 and 30 years of age.

In this thesis I wanted to discover the views and experiences of young people who were able to make their own decisions about their healthcare. As a result I restricted myself to

individuals aged between 16 and 25, as they are more likely to consult health practitioners on their own rather than defer to parental guidance. In order therefore to best align this thesis with the terms used in the literature, as well as the WHO definitions described above, I will use the terms young people and youth interchangeably.

In most primary care research the term 'patient' is used however for mental health research 'service user' is more commonly adopted. As this thesis is located with both research contexts and in an attempt to lighten the narrative I will use both these two terms.

I will use both GP and PCP throughout this thesis for the following reasons. As participants represented different members of the primary care team, I will refer to them collectively as primary care professionals. However in other instances such as studies which refer specifically to GPs (as is often the case in the primary care mental health literature) and when describing individual research team members I will use the term GP so as to inform the reader that I am indeed specifically referring to GPs and not PCPs in general.

### ***Statement of authorship***

The protocol for the study was designed by the grant holders including Professor Andre Tylee (AT), Dr Diana Rose (DR), Joanna Murray (JM), and Professor Helen Lester (HL). I was the sole researcher working on the study and recruited all the young people who took part in the study. I trained all the young service users for their role as focus group co-facilitators with assistance from DR. When the original funding for the 3 year study ended I was successful in obtaining funding for another year to explore two additional objectives of presenting the quality indicators to primary care professionals through focus groups and interviews as well as undertaking further analysis of the data from the focus group and interviews with young people which I had conducted as part of the original project. I conducted all the data collection in collaboration with the young service users, and the analyses with assistance from both the research team and young service users. I am the sole author of this thesis.

## CHAPTER TWO: LITERATURE REVIEW

This chapter provides the background for the thesis. It covers the following five areas:

- The epidemiology of mental health problems in young people, vulnerable groups, young African–Caribbean<sup>1</sup> men and young Asian women. I review methodological issues within youth psychiatric epidemiology, risk factors associated with youth mental health problems and continuity into adulthood.
- The three major issues affecting the management of mental health problems in primary care which are: under-presentation by patients; problems with recognition and subsequent referral to mental health services. I will also review these issues with specific reference to young people and youth with African-Caribbean and Asian backgrounds.
- Lay and professional perspectives on seeking help for mental health problems and the role of primary care including the methodological limitations of survey studies. Lay explanatory models of help seeking will be reviewed.
- The role of quality improvement in primary care mental health. Quality improvement will be defined, and existing initiatives and practitioners' views on quality will be discussed.
- Patient involvement in primary care and mental health service research. The role of patient surveys, patient involvement in questionnaire design, data collection and the development of quality indicators will be presented. Youth participation in health service research will also be reviewed.

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<sup>1</sup> I will use the term African-Caribbean to describe people who are themselves (or descend from) these regions. In recognition of the wide range of terms used in the literature I will use the terminology employed by the authors when referring to a specific study.



## **Inclusion criteria and search strategy**

Initially I conducted a search of PSYCH Info database from 1987 until 2003 when I first began my thesis work. The following search terms were used: “mental health problems”; “mental disorders”; “young people”; “young adults”; “adolescents”; “primary care”; “general practitioners”; “quality indicators”; “quality of care”; “participatory research”; “service user involvement” and ‘patient involvement’. In total, 966 papers were identified. The search mainly identified studies about specialist mental health care and CAMHs. Most of these were excluded because they were not relevant to the role of primary care. Of the studies about secondary care only those that referred to primary care or improving the quality of healthcare for young people were included.

Additional searches using the same search terms were completed on ASSIA and MEDLINE over the course of the thesis (i.e. until September 2010) and relevant literature has been found through hand-searching and identifying key reports and publications in the grey literature. I also received a monthly auto alert of the first Psych Info search results.

As noted above, there is a wide variation of age groups included in studies about young people. Young people aged 16-25 years are included in studies about children and adolescents as well as those about adults. Because of this, it was difficult to explicitly define studies that sample 16-25 year olds. Therefore I made the decision to include studies with a wide age range. Although I will focus on studies that sample 16-25 year olds, I will also include studies that report on under-15 year olds if either older age groups are included, or they are related to follow-up studies of older age groups (from 16 year olds onwards). Where relevant I also include studies with adult samples, focussing on those that report age differences.

## **Epidemiology of youth mental health problems**

This section describes the epidemiology of mental health problems in young people and will attempt to illustrate differences between specific groups of young people.

### ***UK-Based Studies***

Table 1 illustrates the prevalence rates of mental health problems in young people reported by studies conducted in the UK. The data shows that young people aged 16-24 have higher rates of psychiatric morbidity compared to younger age groups.

Ford and colleagues (2003) and Green and colleagues (2005) conducted the two main UK epidemiological studies reporting mental health problems in young people over the last 12 years. Meltzer and colleagues (2003a) conducted a follow-up study of the survey by Ford and colleagues and found that young people aged 13-15 at Time 1 were more likely to have developed an emotional disorder than younger age groups. Clements and colleagues (2008) conducted a follow-up survey of the sample from the Green and colleagues study and found that young people 14-16 years at time 1 were more likely to have developed an emotional disorder compared to younger age groups.

The findings from the survey conducted by Singleton and colleagues (2000) show that neurotic disorders were higher for young people aged 16-24 compared to those aged 5-15 found in the survey by Ford and colleagues (2003). They also found that substance dependence was higher amongst 16-29 year olds than any other age group (Singleton et al. 2000). In an earlier study, Meltzer and colleagues (1993) reported that 16-19 year olds had the highest rates of alcohol and drug dependence.

This suggests that there may be a cohort effect: 16 and 17 year olds in the earlier 1993 study would, by 2000, have moved into the 20-24 year old group and were continuing to exhibit high levels of substance and alcohol abuse. Singleton and colleagues (2000) also found that young people aged 16-24 were more likely to have 2 or more disorders occurring at the same time than older age groups. The authors noted that this was probably due to the high rates of substance use found in 16-24 year olds.

The incidence of schizophrenia peaks for men between the ages of 10 and 25 and for women between the ages of 25 and 35 (Buchanan & Carpenter 2005). Because schizophrenia is a chronic disorder, prevalence increases with age (Singleton et al. 2000). Prevalence rates for psychotic disorder (defined as mood disorders and schizophrenia) found by Singleton and colleagues (2000) are in line with reported prevalence rates for bipolar disorder in 16 to 19 year olds in the 2007 UK adolescent survey (Clements et al. 2008).

**Table 1: Epidemiological studies conducted in the UK**

Study	Age group/sample	Disorder/symptom	Prevalence rate
Ford et al 2003	5-15 year olds	Any mental disorder	10%
		Conduct disorder	5%
		Emotional disorder	4%
		Hyperactive	1%
		Autistic disorders and Eating disorders	0.5%
Green et al 2005	5-16 year olds	Autistic and eating disorders	1.3%
		Emotional disorders	3.7%
		Hyperkinetic	1.5%
		Conduct disorder	5.8%
		Any disorder	9.6%
Meltzer et al 2003	young people aged 13-15 years at Time 1 (i.e. aged 16-18 at Time 2)	Emotional disorder	5%
	Young people aged 5-7 at Time 1 (aged 8-10 at Time 2)	Emotional disorder	3%
Clements et al 2007	16-19	Bipolar disorder	0.1-0.3%
	young people aged 14-16 years at Time 1	Emotional disorder	5%
	young people aged 5-7 at Time 1	Emotional disorder (See page 83 of report)	2%
Singleton et al 2000	16-19 year olds	Neurotic disorders	13.3%
	20-24 year olds	Neurotic disorders	15.8%
	16-19r olds	Drug dependence	12.6%
	20-29 yr olds	Drug dependence	13.8%
	20-24 year olds	For mild dependence on alcohol	15.0%
	of 35-39 year olds	For mild dependence on alcohol	6.6%

**Table 1: Epidemiological studies conducted in the UK**

Study	Age group/sample	Disorder/symptom	Prevalence rate
Singleton et al 2000 con't	16-19 year olds	2 or more disorders (neurotic, psychotic and substance abuse)	7%
	20-24 year olds	2 or more disorders (neurotic, psychotic and substance abuse)	10%
	60 year and over	2 or more disorders (neurotic, psychotic and substance abuse)	1% or less
	16-19 year olds and 20-24 year olds	Psychotic disorder	0.2%
	40-44 year olds	Psychotic disorder	1.0%
McClure 2001	15-19 year olds	male suicide	0.0052%
		Female suicide	0.0013%
Harrison et al 1997	African-Caribbeans aged 20-29	Incidence of psychosis	0.033%
	African-Caribbeans aged 16-19	Incidence of psychosis	0.016%
	African-Caribbeans aged 30-39	Incidence of psychosis	0.020%
	African-Caribbeans aged 50-59	Incidence of psychosis	0.003%
Meltzer 2003b	young people (5-17 years old ) looked after by local authorities	any mental health problem	45%
		conduct disorder	37%
		emotional disorders	12%
		Hyperactive disorders	7%
Gill et al 1996	Homeless people aged 16-24	drug dependence	57% (highest proportion)
		neurotic disorder	36% (highest proportion)
		alcohol dependence	28% (highest proportion)

### ***International Surveys***

Table 2 shows the epidemiology of mental health problems in young people as reported by surveys conducted outside the UK. Roberts and colleagues (1998) found that studies' including older age ranges reported higher prevalence rates of mental health problems in young people. Other studies extending the sample age to 16 and 17 year olds also reported higher levels of psychiatric morbidity amongst children and young people (Singleton et al. 2000). From this evidence it can be argued that older youth are more likely to have a mental health problem than younger age groups.

In the USA, Kessler and Walters (1998) report prevalence rates similar to that found by Singleton and colleagues (2000) in the UK Survey. Other studies outside the UK, also support Singleton and colleagues findings, reporting substance abuse as the most frequent presentation of psychiatric disorder for 14-24 year olds (Wittchen et al. 1998) and 18-24 year olds (Bijl et al. 2002) with the peak for alcohol disorders occurring at age 16-17 (Nelson & Wittchen 1998). Kandel and colleagues (1999) found that the rate of substance use and any other psychiatric co-morbidity was slightly higher for young people aged 14-18 compared to an adult sample aged 18 and above.

Eating disorders affect a disproportionately large number of young adults, particularly females aged between 15 and 30 years old with similar prevalence in the UK and USA being reported. In the UK, total incidence rates for anorexia nervosa is forty times higher in women compared to men with the highest rate found in 10-19 year olds (Turnbull et al. 1996). US studies show that 13-19 year olds experience anorexia nervosa five times that of 20-30 year olds (Pawluck & Gorey 1998).

**Table 2: International epidemiological studies**

Study	Country	Study sample	Age group/sample	Disorder/symptom	Prevalence rate
Roberts 1998	USA	Community sample	0-15 year olds	Any psychopathology	1-51% (mean 15.8%)
			Pre-schoolers 0-6 or 7 year olds	Any psychopathology	8%
			Adolescents aged 12 or 13 years	Any psychopathology	15%
			% wider age ranges up to 15 years old	Any psychopathology	18%
Kessler and Walters 1998	USA	Community sample	15-24 year olds	Any depressive or anxiety disorder	3.1% and 1.6%
				Life time prevalence of major depression	15.9%
				Life time prevalence of minor depression	9.9%
Kandel et al 1999	USA	Community sample	14-18 year olds	Of those with a substance use disorder also had any anxiety, mood or disruptive behaviour disorder	76%
			18 years and older	Of those with a substance use disorder also had any anxiety, mood or disruptive behaviour disorder	23.4%
Aarons et al 2001	USA	Young people aged 6-18 across five care settings in the USA	alcohol and drug services	Substance use	82.6%
			child welfare	Substance use	19.2%
			juvenile justice	Substance use	62.1%
			mental health	Substance use	40.8%
			and public school services for young people with serious emotional disturbance	Substance use	23.6%

**Table 2: International epidemiological studies (continued)**

Study	Country	Study sample	Age group/sample	Disorder/symptom	Prevalence rate
Garland et al 2001	USA	Young people aged 6-18 across five care settings in the USA	6-18	Any disorder	54%
			alcohol and drug services	Any disorder	60.3%
			child welfare	Any disorder	41.8%
			juvenile justice	Any disorder	52.1%
			mental health	Any disorder	60.8%
			and public school services for young people with serious emotional disturbance	Any disorder	70.2%
Sawyer 2007	Australia	Community sample	13-17 year olds	Any mental health problem	13% parent report/ 19% young person report
Fergusson et al 2003	New Zealand	1265 young people studied from birth to age 21 (community sample)	Young people aged 18	Psychotic symptoms and cannabis dependence	Rate ratio = 3.7; 95% CI 2.8 – 5.0 $p < 0.0001$
			Young people aged 21	Psychotic symptoms and cannabis dependence	Rate ratio = 2.3; 85% CI 1.7-3.2; $p < 0.0001$
Heron 2007	USA	Community sample	15- 19 year olds	completed suicide	0.0082%
			20-24 year olds	completed suicide	0.0125%

### ***Methodological issues in youth psychiatric epidemiology***

In addition to differences in sampling noted above, there are a number of issues associated with adolescent and youth psychiatric epidemiology:

- Some research instruments have a higher diagnosis threshold meaning fewer participants meet criteria (Edelbrock & Costello 1998).
- It is often difficult to ascertain differences between normal behaviour and that which represents some form of psychopathology (Costello 1989).
- Prevalence rates differ according to the identity of the respondent (Roberts et al. 1998). For example, prevalence rates differ between scores provided by parents and young people (Sawyer et al. 2007).

Epidemiological studies have also found a difference in prevalence rates according to the identity of who is asking the question. Traditionally researchers have administered questions but I shall argue that results may also differ if data is collected by other young people, e.g. peer interviewers. This concept will be discussed in more detail later where I will review patient involvement in health services research.

### ***Suicide and deliberate self-harm***

Youth suicides are associated with having a major psychiatric disorder (Gould et al. 2003) or depressive disorder (Shaffer et al. 1996; Houston et al. 2001). In addition, an association has been found between substance abuse and an increased risk of suicide for young people (McClure 2001). As shown in table 1, McClure (2001) reported suicide rates for young people aged 15-19 in the UK which are slightly lower than the prevalence rates found by Heron (2007) in the USA, but, as noted earlier, this may be due to methodological differences between the studies.

Deliberate self-harm occurs in 7% of 15 and 16 year old pupils, with girls nearly 4 times more likely to self-harm than boys (Hawton et al. 2002). An 18-month follow-up of 2,406 people from the survey by Singleton and colleagues (2000) found that the incidence of onset of suicidal thoughts was highest amongst 16-24 year olds compared to other age groups (Office of National Statistics 2003). However, 16-24 year olds also had the highest recovery rate compared to other age groups. The authors suggested that this pattern of high incidence and recovery may have been due to periods of emotional distress that can occur during the transition from childhood to adulthood. In addition, the authors mentioned that this relationship may illustrate that suicidal thoughts lead to the higher rates of self-harm found in 16-24 year olds, and not completed acts of suicide.



McClure (2001) found that males aged 15-19 were the only group to show an increase in suicide rates between 1970 and 1998 and suggested that this increase was due to an increase in psycho-social stressors. However, since then, the suicide rate in the UK has decreased for young people aged 10-19 years old (Windfuhr et al. 2008) although rates remain consistently higher for males (Brock et al. 2007). Reasons for this include a reduction in poisoning by gas exhaust methods through the addition of catalytic converters to cars as well as exposure to fewer risk factors for suicide such as unemployment and divorce (Biddle et al. 2008) In addition, the suicide prevention strategy developed as part of the National Service Framework for mental health services in the UK may have been a possible factor in reducing what had been an upward trend (Department of Health 2002).

### ***Continuity between childhood and young adulthood***

The following studies provide evidence to suggest that mental health problems in childhood have been found to persist into adulthood.

A UK longitudinal study found that depressed children and adolescents had an increased risk of affective disorders, psychiatric treatment and hospitalisation (Harrington et al. 1999). In addition, conduct and oppositional disorders in childhood are associated with an increased risk of subsequent adult depression (Kim-Cohen et al. 2003). Although an association has been found between environmental and social risk factors during childhood and adult mood disorders, mental health problems in childhood do not predict the type of mental health problem that may develop in adulthood (Wals & Verhulst 2005).

Commentators have noted that there are many other factors that contribute to the onset of mental health problems and to focus on specific disorders alone may be too simplistic (Maughan & Kim-Cohen, 2005). These studies highlight the point that mental health problems in childhood or adolescence should not merely be considered as a developmental phase or 'teenage angst', but something that may well persist into adulthood. With this in mind the role of prevention and the identification of protective factors are hugely important but the literature on prevention and youth health promotion will not be reviewed as it is outside the scope of this thesis.

### **Risk factors**

The studies reviewed above illustrate that young people aged 16-24 years old have a higher prevalence of mental health problems compared to 5-15 year olds (excluding conduct disorders that tend to cease after childhood has ended). Hence being older could be considered to be a risk factor for mental health problems. This occurs at a time when 16-24 year olds are developing their independence from parents, family members and

pastoral carers and as a result they are increasingly reliant upon themselves to manage and make decisions about their mental health problems.

Young people with a substance use disorder have been found to be three times more likely to have a co-occurring psychiatric disorder than those without a substance use disorder (Kandel et al. 1999). In a longitudinal study in Australia, Patton and colleagues (2002) found that cannabis use predicted the onset of depression and anxiety in young people with daily users most at risk. An association has also been reported between cannabis and conduct disorder and depression in young people aged 13-17 (Rey et al. 2002). As shown in table 2, Fergusson and colleagues (2003) found that young people who met criteria for cannabis dependence had elevated rates of psychotic symptoms. The increased risk of psychosis in young people is more likely with heavy use of cannabis (Zammit et al. 2002) and in those who both use cannabis and are predisposed to developing schizophrenia (Henquet et al. 2005).

Patel and colleagues (2007) report that a history of abuse, parental marital breakdown, poor educational attainment and bullying were associated with youth mental health problems. Parental mental health problems (Zwaanswijk et al. 2003) physical illness (Clements et al. 2008; WHO 2001) and co-morbid and recurrent mental health problems (Costello et al. 2003) have also been found to be risk factors for mental health problems in young people.

As well as individual factors which may predispose a young person to develop a mental health problem, a number of social groups are considered to be at higher risk of having mental health problems. These will be outlined in the following two sections.

### **Vulnerable groups**

Tables 1 and 2 illustrate that substance use and psychiatric disorders are highly prevalent in young people from social care settings in the UK and USA (Meltzer et al. 2003b; Aarons et al. 2001; Gill et al. 1996). The prevalence rates reported in these studies were higher than those found in general population surveys. Substance use was also found to be higher for young people aged 16-18 compared to younger age groups (Aarons et al. 2001).

Homeless youth aged 16-24 years are twice as likely to have a mental health problem compared to their domiciled counterparts (Craig & Hodson 2000; Craig & Hodson 1998). In the UK, Gill and colleagues (1996) found that compared to other age groups, the highest proportion of homeless people with drug dependence, a neurotic disorder and alcohol dependence were young people aged 16-24 years. In a Canadian study on mortality rates among street youth, suicide and drug overdoses were found to be the first and second

most likely causes of death respectively (Roy et al. 2004). But since mental health problems have been found to precede homelessness for young people (Rohde et al. 2001; Craig & Hodson, 1998) it is difficult to determine the direction of the causal relationship.

### **Specific ethnic groups: Asian females and African-Caribbean males**

As the research described in this thesis seeks to understand the views of a wide range of young people including those that have higher prevalence rates of mental health problems, two ethnic groups of particular interest in South London are Asian females and African-Caribbean males. I will therefore present an overview of the mental health problems specifically reported in the literature for these two groups. There are a number of theories that have been put forward to explain why ethnic minorities experience higher rates of mental health problems though it is beyond the scope of this thesis to provide a detailed review of these. I will however present a brief outline of the main arguments to provide some contextual framework.

#### ***Prevalence of mental health problems in African-Caribbeans and Asians***

In the UK, the prevalence of common mental disorders in adults has been found to be similar between Asians and Whites (Bhugra et al. 2001). But Asian women aged 16-24 years self-harm over two and a half times more than their white counterparts and seven times more than young Asian men (Bhugra et al. 1999a; Bhugra et al. 1999b). Asian's who self-harm are also more likely to be young, female and married (Merrill & Owens, 1986).

Although the prevalence of common mental disorders has been found to be similar between African-Caribbeans and Whites (Shaw et al. 1999), there is a consensus in the literature that African-Caribbean's in the UK have a higher rate of psychosis compared to Whites and other ethnic groups. Fearon and colleagues (2006) found that incidence rate ratios were particularly high for all ethnic minority groups but especially in African-Caribbeans and Black Africans, although there was no evidence of an age effect. However, in an earlier study (detailed in table 1), Harrison and colleagues (1997) reported that African-Caribbeans aged 20-29 years had the highest incidence of psychosis. These findings are supported by Bhugra and colleagues (1997) who found that a majority of African-Caribbeans with diagnosed schizophrenia in the UK are young men aged 18-29 years.

These studies suggest that in the absence of protective factors young African-Caribbean men and young Asian women may be more vulnerable to developing mental health problems than young people from a majority ethnic background. Therefore, health services

research that aims to better meet the needs of young people generally should also specifically take account of the views of young people from these groups.

### ***Theories explaining the high incidence of mental health problems in ethnic minority groups***

There have been a number of explanations put forward for the disparities in mental health found between ethnic minority and majority groups. It was initially thought that psychiatrists were misdiagnosing behaviours exhibited by people from ethnic minorities as psychotic. However, this argument has been largely discredited due to lack of empirical evidence (Morgan & Hutchinson 2010; Selten & Hoek 2008). A second explanation, also now largely discredited for the same reason, argues that individuals who are predisposed to developing schizophrenia are more likely to migrate (Odegard 1932). Today post migratory factors are generally thought to be more important than pre-migratory conditions (Bourque et al. 2009) and the theory that is most widely accepted is that individuals from ethnic minority backgrounds are exposed to greater social disadvantages (e.g. racism and discrimination) which contributes to their greater risk of mental health problems (Coker et al. 2009; Cooper et al. 2008).

### ***Conclusions***

Mental health problems represent a significant burden for young people. With the exception of conduct disorders in childhood, the prevalence of psychiatric disorders increases with age. Hence, young people aged between 16 and 25 are more likely to be affected by mental health problems than those in younger age groups.

A significant proportion of psychiatric disorders affecting this age group are substance misuse disorders which tend to cease after individuals reach the age of 30. However, drug and alcohol use is associated with increased risk of mental health problems in youth. There is also strong evidence to suggest that problems in youth can persist into adulthood. Having a mental health problem during this period of young adulthood also increases the risk of suicide.

The literature on the mental health of ethnic minority groups suggests that in the absence of protective factors, young African-Caribbean males and young Asian females are particularly vulnerable to mental health problems compared to their white counterparts. Young people in receipt of social services intervention or who are homeless have an increased likelihood of having a mental health problem. With this important public health

concern now clear, I will now review the evidence regarding the role of primary care in managing youth mental health problems.

## Managing mental health problems in primary care

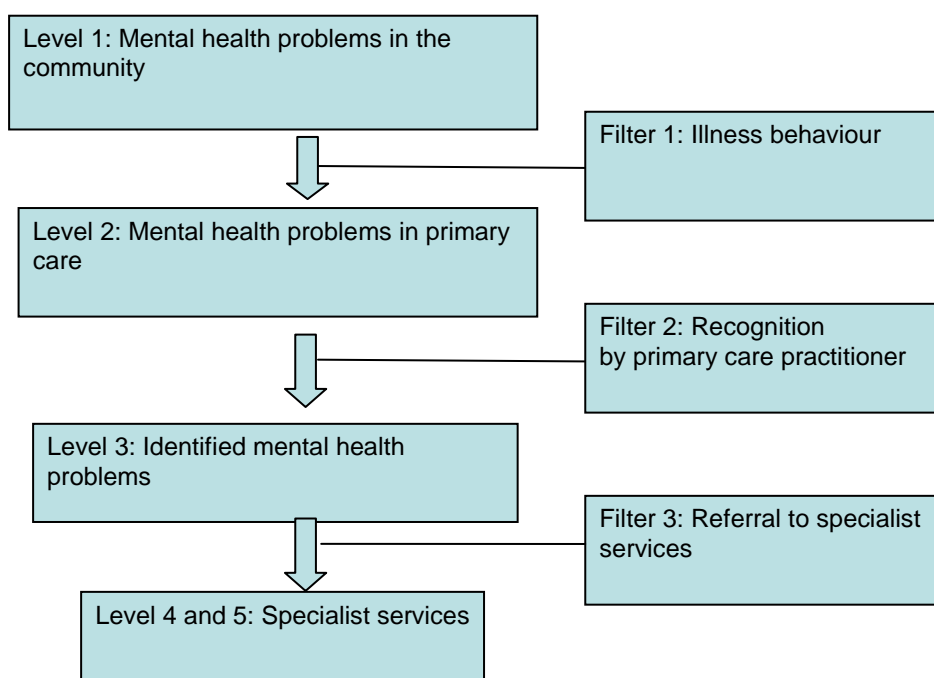
In spite of the fact that most of the literature about managing mental health problems in primary care is based on adults, many of these studies also include young adults in their samples. Since this group fall within my research range, at least in the upper age group, it is appropriate to review this literature prior to focussing on studies specifically about young people.

### *Goldberg and Huxley Model of Pathways to Care*

The Goldberg and Huxley model (figure 1) describes levels that demarcate the pathway from the community to specialist mental health services for people with mental health problems (Goldberg & Huxley, 1992; Goldberg & Huxley, 1980). The model suggests that passing from one level through to the next is determined by the following:

- Illness behaviour, i.e. the manner in which or even, whether patients present to primary care.
- The health care practitioner's ability to diagnose (recognition) and refer a patient (referral).

**Figure 1: Pathways to care model (adapted from Goldberg & Huxley, 1992)**



### ***Presentation of mental health problems in primary care***

Over a quarter of adult GP attendees have at least one psychiatric disorder as defined by ICD-10 criteria (Ustun et al. 1995) and ninety percent of common adult mental health problems are usually treated in primary care alone (Goldberg & Huxley 1992; Shepherd et al. 1966). However, between a third to a half of all people with depression do not consult a GP (Bebbington et al. 2000; Lepine et al. 1997). One of the reasons for this may be because patients may perceive psychological symptoms as less worrisome than physical symptoms (Prior et al. 2003) and therefore may not mention emotional distress in consultation (Cape & McCulloch 1999). Patients mainly present with physical symptoms (Kirmayer et al. 1993), which makes recognition of depression difficult (Bridges and Goldberg, 1985). Patient presentation is also affected by whether their attribution style is somatising, normalising, or psychologising (Robbins & Kirmayer, 1999). Patients with a normalising style are most commonly found in primary care and are also less likely to have their mental health problems detected (Kessler et al. 1999).

### ***Recognition of mental health problems in primary care***

Whilst GPs have been shown to recognise most patients with more severe depressive symptoms (Thompson et al. 2000), cross-sectional studies have shown that overall between 30% and 50% of adult patients with mild, moderate or severe depression go unrecognised in primary care in the index consultation (Freeling et al. 1985; Bridges et al. 1985; Goldberg and Huxley, 1980) but that most people go on to have their depression recognised over a series of consultations (Kessler et al. 1999). Patient characteristics such as gender (Marks et al, 1979) previous history of depression (Wittchen et al. 2001) and presenting with social or psychological problems (Ormel et al. 1990) have been found to have an effect on recognition of depression in primary care. Tylee (1995) found that depression was ten times less likely to be recognised if the first psychiatric symptom was mentioned late in the consultation, a phenomenon that commonly occurs in primary care. Early work found that GPs ability to detect mental health problems varied (Millar & Goldberg 1991; Goldberg & Huxley 1980) and was dependent on their knowledge, skills and attitudes (Marks et al. 1979). GPs with good interview skills such as increased eye contact, fewer interruptions, the use of open questions and good listening skills were more likely to detect common mental health problems (Marks et al. 1979).

## **Illness behaviour: the under-representation of young people with mental health problems**

Studies have shown that only 13-14% of young people with mental health problems seek help from services including health, education and social care (Mauerhofer et al. 2009; Ford et al. 2003; Sawyer et al. 2001). With regard to primary care in particular, young people are the least likely to seek help for their mental health problems compared to older age groups. Using data from the UK National Survey of Psychiatric Morbidity, Bebbington and colleagues (2000) found that the likelihood of contacting a GP increased with age from 16-24 year olds, to 25-34 year olds, to 35-44 year olds, peaking at 44-54 year olds and decreasing for 55-64 year olds. However, this trend was only statistically significant between 16-24 year olds and 44-54 year olds with the latter contacting GPs 53% more than the former.

Commander and colleagues (1997) found that of the GHQ-30 cases identified, 16-29 year olds were the least likely to consult a GP and have their mental health problems identified compared to 30-44 year olds and 45-64 year olds. Similar results have been found by a more recent regional survey in the UK. Oliver and colleagues (2005) investigated lay and professional patterns of help-seeking via a postal- questionnaire sent to a random sample of 16-64 year olds registered with a general practice in Somerset, UK. They asked participants 'if you felt that your health might be suffering as a result of stress or strain in your life would you consider consulting any of the following: friends and relatives, counsellor, GP, and other please specify'. The proportion of 16-24 year olds with raised GHQ-12 scores (of 4 and above) that would consider seeking help from a GP was the lowest compared to other age groups (12% of females and 7% of males with a GHQ score of 4-7 increasing to 23% of females and 11% of males with a GHQ score of 8-12). As in the study by Bebbington and colleagues (2000), Oliver and colleagues (2005) found that seeking help from a GP was directly proportional to increasing age group from 16-24 up until 45-54. This trend was only statistically significant between 16-24 year olds and 34-44 year olds with the latter indicating they would seek help from the GP 59% more often than the former.

There is a consensus in the literature that severity of symptoms and female gender are associated with GP contact for young people (Mauerhofer et al. 2009; Oliver et al. 2005; Biddle et al. 2004). GP contact has been found to increase for young people prior to suicide (Hawton et al. 1999; Appleby et al. 1996). Biddle and colleagues (2004) found that GHQ score was the strongest predictor of GP contact. Even so, they found that only 8.9% of young women and 7.5% of young men with a GHQ score of 4 or higher sought help from their GP.

Female gender is a significant predictor of professional help seeking even when controlling for severity of symptoms (Rickwood & Braithwaite 1994). Biddle and colleagues (2004) found that female GHQ cases were more likely to have accessed both medical (GP) and non-medical sources of help compared to males with the same GHQ score. For those that did consult their GP, men had a slightly higher mean GHQ score (10) than women (8.5). The authors found weak evidence of a sex difference between these two scores ( $p= 0.07$ ) which led them to posit that males may have a higher threshold for psychological problems than women.

Young people are more likely to consult a GP for physical problems than mental health problems. Ferrin and colleagues (2009) found that of 13-17 year olds in London, only 2.2% consulted for psychiatric or behavioural problems, but that over 20% visited their GP for respiratory illness and skin diseases. This suggests that in spite of the burden of psychiatric morbidity experienced by young people described in part 1, a large proportion of this group are not having their mental health needs met by primary care.

### **Diagnosis: Recognition of mental health problems**

Identification of teenage mental distress is complex (Jacobson et al. 2002), associated with increased physical symptoms and often not recognised by GPs (Kramer & Garralda, 1998). A review by Zwaanswijk and colleagues (2003) found that GP recognition was positively affected by training, specific interview techniques and the availability and use of screening measures. GP problem recognition was found to be lower for young people that the GP did not know well and with whom they had a shorter consultation time. Conversely, more recent studies have shown that young people's views (rather than GP characteristics) are more likely to be associated with identification of a young person's mental health problems. Haller and colleagues (2009) found that youth beliefs about the severity of and fears about their mental health problem were strongly associated with GP recognition. GP training in mental health and adolescent health, however, was not associated with correct identification of mental health problems for 16-20 year olds with a high probability of being emotionally distressed. As reported by Zwaanswijk and colleagues (2003), Haller and colleagues (2009) found that continuity of care and more frequent consultations were also associated with GP identification of a mental health problem in young people. In an earlier study, Van Voorhees and colleagues (2005) found that 16-29 year olds were more likely to disagree with their physicians' diagnosis of depression if they disagreed with the statement 'medication is useful' and 'there is a biological cause for depression'. These studies show that young people's perceptions about their mental health problems and the amount of contact they have had with primary care are important factors in recognition of mental health problems.



Zwaanswijk and colleagues (2005) found that there was limited agreement between GP psychological diagnoses and parent, teacher, and adolescent reports of psychological problems, pointing to a disparity between practitioners and lay views about what is considered to be a mental health problem. Since, as noted in the section above, young people who openly present with psychological symptoms are more likely to be correctly diagnosed, it can be argued that if young people (and their parents) do not consider their symptoms to be indicative of a mental health problem, they are less likely to be offered appropriate help.

## **Referral to mental health services**

Mild to moderate common mental health problems are largely treated within primary care settings. More severe cases which may also involve self-harming or a suicide attempt and other categories of mental health problems such as eating disorders, psychotic disorder and conduct disorders are likely to be referred to Tier 2 and Tier 3 specialist services. Very severe cases are usually managed in an in-patient unit (Tier 4).

Although there has been little research about the factors affecting GP referrals to mental health specialists for young people (Kramer & Garralda 2000) the following two characteristics have been found to be associated with referrals to mental health services. Firstly, young people with severe and complex behavioural problems are more likely to be referred (Kramer & Garralda 1998). Secondly, parents are more likely to recognise behavioural disorders and request a referral (Kramer & Garralda 2000). However, as will be discussed in the following section, there is often a disparity between what practitioners and parents consider to be a useful intervention for a young person with a mental health problem. Taking this argument further, there may also be differences between the opinions of young people and their parents as to what constitutes a mental health problem. So, although parents can request a referral, a young person may not agree, or want to be seen by a specialist. Parents may also be less involved in the help seeking decisions of older youths aged 16-25, compared to those aged 15 and under.

NICE guidelines for the management of depression in children and young people offer the following protocol for referral to specialist services (NICE 2005):

- depression with two or more other risk factors for depression
- depression where one or more family members (parents or children) have multiple-risk histories for depression
- mild depression in those who have not responded to interventions in tier 1 after 2–3 months
- moderate or severe depression (including psychotic depression)

- signs of a recurrence of depression in those who have recovered from previous moderate or severe depression
- unexplained self-neglect of at least 1 month's duration that could be harmful to the child/young person's physical health
- active suicidal ideas or plans
- young person or parent(s)/carer(s) request referral.

These guidelines are aimed at practitioners working in community, primary and secondary care settings. But it has been argued that due to the high incidence of common mental health problems in the community, most specialist services cannot manage the referral of all those with moderate or severe mental health problems (Goldberg and Huxley 1992). But there are a number of service models that have enabled primary care practitioners to access the skills of mental health specialists and improve the chances of referral. Gask and colleagues (1997) described two main models of mental health work in primary care; 'shifted out-patients' whereby specialist staff conduct clinical work in the primary care setting and consultation-liaison which includes training, consultation and joint case work. This model has been found to work well in managing young people's mental health problems. Wiener and Rodwell (2006) conducted an evaluation of a CAMHs service operating within primary care and found that informal consultation-liaison was used more than formal consultation. Referrals to specialist CAMHs increased and GPs found the service useful and accessible. Another study of consultation-liaison in primary care found that the service encouraged GP referrals to CAMHs that would have otherwise not taken place (Abrahams & Udwin 2002).

### ***Improved Access to Psychological Therapies***

Since this study was conducted the new Improved Access to Psychological Therapies (IAPT) initiative has been developed. The model provides access to a low or high intensity therapist often through self-referral (Brown et al. 2010). An evaluation of the two pilot sites has found that self-referrals have been more prominent for BME groups which suggest that the IAPT model encourages traditionally under-represented groups to access therapeutic services (Clark et al. 2009). Preliminary studies have shown that the IAPT model can deliver good clinical outcomes in routine practice (Richards & Suckling 2009) but IAPT services are aimed primarily at individuals aged 18 and above. Special interest groups have published practice guidelines to improve access to therapies for particular groups in the hope that the barriers that are specific to particular patient groups including black and minority ethnic patients, perinatal patients, older people, children and young people, offenders and those with learning disabilities might be addressed. Some PCTs are extending the inclusion age to patients aged 16 and above which may ensure that talking

therapies are available for younger patients. This is being led by Bury PCT although guidelines of best practice for this group have yet to be published (NHS Bury 2010).

### **Help-seeking for Ethnic Minorities**

Much of the UK literature about ethnicity and mental health focuses on adults and not young people. Studies have shown that pathways to care for African-Caribbean people with mental health problems are more complex (Bhui et al. 2003) and compulsory admissions are more frequent compared to their White counterparts (Davis et al. 1996). This trend is markedly significant for ethnic minority youth. Young people aged 13-17 with a diagnosis of psychotic disorder from Black African, Black Caribbean and Black British backgrounds are more likely to be admitted (and detained upon admission) than White youth (Tolmac & Hodes 2004). In addition, African-Caribbean's aged 16-30 are over 4 times more likely than their white counterparts to be compulsory admitted to psychiatric hospital (Morgan et al. 2005).

For psychotic disorders, GP referral is less likely for African–Caribbean and Black African patients compared to White British patients (Morgan et al. 2005). There is conflicting evidence from the UK literature regarding differences between GP consultation rates for common mental disorders among minority-ethnic communities and Whites (Shaw et al. 1999; Gillam et al. 1989). The evidence is more consistent regarding GP recognition. GP detection of mental health problems has been found to be lower in African-Caribbean and Asian patients compared to English patients (Shaw et al. 1999; Odell et al. 1997).

The GP has been reported as a main referral route for specialist services for Asian families however concerns about the stigma of mental illness was found to be a significant factor in deterring families from using CAMHs and other specialists services once referred by their GP (Bradby et al. 2007). Chew-Graham and colleagues (2002) found that Asian women felt that seeking help from primary care for psychological distress would damage the family's "izzat" (honour). This fear was maintained by the 'community grapevine' of gossip between members of the community and a sense of cultural incongruity between the GP and themselves. These studies show that ethnicity has an impact upon help seeking behaviour.

Most of the studies from the UK lack detail about young people aged 16-25. The US literature is more developed regarding ethnic youth differences in seeking help for mental health problems. This will be reviewed in the next section.

### ***US studies on ethnicity and help seeking***

US studies have shown that depressed African-American youth are less likely to

receive professional help compared to other ethnic groups (Wu et al. 2001)<sup>2</sup>. In particular, Blacks are less likely to receive counselling than Whites (Kodjo & Auinger 2004), Hispanic youth<sup>3</sup> have been found to use health services less than White non-Hispanics (Pumariega et al. 1998) and have higher rates of un-met mental health needs compared to White youth (Kataoka et al. 2002). However, there is also conflicting evidence from US studies regarding the differences in help seeking between racial groups. A systematic review of differences between children and adolescents aged 17 years and younger found eight studies which reported that Blacks received less primary care services and four studies which found no differences between racial groups. The same review reported that Hispanic youth received less primary care in 6 studies but that no differences were found for Hispanics in 5 studies (Elster et al. 2003). Ethnic minority youth are reported to prefer seeking help from informal sources of help than health services (McMiller & Weisz 1996; Barker & Aldeman, 1994).

### ***Candidacy and Recursivity***

There are two concepts which are useful to consider when investigating help seeking. Firstly, candidacy refers to the process by which individuals are deemed eligible both by themselves and professionals to use healthcare services (Dixon-Woods et al. 2006). This eligibility is negotiated through interactions between an individual and professionals. This is a dynamic process which is influenced by perceptions of health and healthcare services. Once an individual has presented to health services, professionals make judgements which in turn impacts upon the individual's continued use of services such as being referred or the way in which symptoms are interpreted.

Secondly, 'recursivity' acknowledges that experience of illness and service use also impacts upon help seeking decisions (Rogers et al. 1999). Cultural social norms about the meaning of symptoms lead to different illness management strategies. For example, those that see tiredness as an illness are more likely to seek medical attention. Others may consider tiredness as a normal aspect of their lives and so would not consult a health professional. Previous experience of services can also affect an individual's assessment of their own eligibility to use services. Poor satisfaction with previous service use has been linked to failure to attend on subsequent occasions. In addition, other people's experiences can indirectly affect service use. Hearing positive or negative feedback from others in one's social network can inform an individual's decision to consult. Previous experiences of consulting informs individuals of the symptoms and ways of presenting that health

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<sup>2</sup> Access to the US healthcare system is largely affected by medical insurance. This is a significant difference between UK and US healthcare systems needs to be taken into account when reviewing US studies as the same monetary barriers do not exist in the UK or Europe.

<sup>3</sup> In US studies, the terms 'Hispanic' and 'Latino' refer to individuals from central and South America as well as the Caribbean.

professionals are more likely to respond towards. In this way patients learn how to shape the way they interact during consultation which in turn meet the requirements of a legitimate illness and service use (Rogers et al. 1999). The notions of candidacy and recursivity illustrate the role that lay knowledge plays in help seeking. Lay and practitioner views about the role of primary care for mental health problems are presented in the following section.

### ***Conclusions***

Young people are less likely to seek help from primary care for their mental health problems compared to other age groups. Although improving GP skills does improve recognition, more recent studies have shown that young people's views about their mental health problem are more closely associated with GP recognition than GP characteristics such as level of training. GPs consult with specialists and often rely on referrals to CAMHs and adult mental health services to manage the mental health needs of young people in primary care. Perception of need, severity of symptoms, gender and ethnicity are each associated with youth access to healthcare for mental health problems. However, the decisions made by young people involve not only the factors above but are also influenced by their opinions about which source of help is most appropriate, and which aspects of consulting health practitioners are considered important. Professional and self- assessment of one's eligibility for medical care also determines whether or not help is sought. Similarly, cultural beliefs about illness and previous experience of service use can impact upon subsequent help seeking.

### **Lay and practitioner views about the role of primary care for mental health problems**

The views of young people and primary care professionals regarding help seeking for mental health problems are each important factors to consider when assessing the role of primary care for youth mental health problems.

#### ***Views on appropriate sources of help for a mental health problem***

A number of survey studies have focused on health services in general while not asking specifically about primary care.

When young people are asked to choose a source of help for mental health problems family doctors are often cited as the least popular (Klein et al. 2003; Boldero & Fallon 1995). Burns and Rapee (2006) found that over half of the young people in their study recommended that a depressed person consult a counsellor, followed by friends and

family. Professionals, psychologists, psychiatrists and doctors were all recommended by under 9.9% of the sample with doctors the least recommended source of support (1.5%). However, Wright and colleagues (2005) found less of a difference with young people aged 18-25 years considering counsellors/psychologists (26.8%) the best form of help for depression, followed by family and friends (25.2%) and the family doctor/GP (22.2%).

By contrast, in the sample of GHQ cases aged 16-24 years identified by Biddle and colleagues (2004), young people were twice as likely to choose friends as a source of help compared to a GP. Rickwood and Braithwaite (1994) also found that young people with a GHQ score of 4 or more sought help from informal sources rather than professionals.

The above studies show that young people consider family doctors to be the least preferable source of help. This may be because they do not believe they are helpful. Marcell and colleagues (2005) asked 210 US high-school students to complete a self-administered survey about case scenarios depicting pneumonia, smoking, initiating sex, and depression. Participants were asked whether they felt 'physicians were effective, trustworthy and confident in diagnosing and treating the problem' and were willing to seek help for that problem from a physician. They found that although adolescents believed that all three (except initiating sex) should be considered a serious health problem, they felt that physicians were effective for smoking and pneumonia but less effective for depression and initiating sex.

Adults appear to be slightly more favourably disposed towards GPs when it comes to depression, although informal sources of help are also prioritised (Riedel-Heller et al. 2005; Priest et al, 1996). However, adult views about the best form of help have been found to differ between types of mental health problem. Angermeyer and colleagues (1999) found that when an individual is seen to be suffering from a psycho-social problem such as family-related and work stress, speaking to a confidant, and attending a self-help group as well as seeing a health professional was deemed appropriate. But if a mental health problem was considered to be a psychiatric disorder or caused by 'uncontrollable influences' health professionals were prioritised above other sources of help.

As noted earlier, although young people attend health services, they are unlikely to discuss their mental health problems there. Klein and Wilson (2002) surveyed 6,748 adolescents from a school-based sample about which health related topic health practitioners should discuss with them and what they actually discussed. Although stress was the most common risk factor, only about a third had discussed it with a health practitioner. This study was limited because the temporal relationship between the identification of risk factors and the consultation was not measured. As a result, they did not know whether a risk factor was identified by the young person before or after the consultation. This

limitation was noted by the authors. However there was a second major limitation which was not discussed by the authors. They asked participants to report whether the health provider they consulted had discussed any risk factors with them but they did not measure whether the young person mentioned the risk factor during the consultation. It would have been useful to know how this affected the outcome of the consultation because the way that a patient presents has a significant impact on the outcome and in particular whether their needs are met.

### ***Young people's views on consulting a GP***

A number of studies have focussed on young people's views of GPs although these have not necessarily limited themselves to those with mental health problems

Kari and colleagues (1997) found that 61% of 12-18 year olds felt they would not know how to register with a GP if or when they left home. They also reported that access for health concerns was problematic due to embarrassment, difficulty in getting a quick appointment, an unsympathetic doctor and belief that their parents will find out. This concern about confidentiality is supported by the findings of Marcell and colleagues (2005) who found that only 5% of high-school students named their primary care physician as a place to get confidential healthcare. Donovan and colleagues (1997) also reported similar results. They found that young people reported difficulties with GP appointments including embarrassment, difficulty getting a quick appointment and an unsympathetic GP.

Jacobson and colleagues (2001) conducted a mixed methods study using questionnaires and focus groups with young people aged 14-18 recruited from practice registers in the four districts of Northern Bro Taf in South Wales. As reported by earlier surveys conducted by Kari (1997) and Donovan and colleagues (1997), young people were concerned about confidentiality, a lack of respect for teenage health concerns and shortness of time allowed for the consultation. Results from the questionnaire showed that 40% were unsure if they could access help for emotional problems, and 54% were uncertain they could receive counselling services through their GP. The research team had intended to conduct 16 focus groups representing four groups of young people: 14 and 15 year old males, 14 and 15 year old females, 16-18 year old males and 16-18 year old females. Only a small proportion of the sample was willing to take part in the focus groups, and as a result only four female and two male focus groups took place (with a majority of 14-16 year olds). In order to recruit a sample representing different age groups, the research team would have needed to employ a more purposeful recruitment strategy such as holding focus groups at schools and youth clubs. Analysis of the focus groups found the following themes; young people did not feel respected by primary care staff; communication with the GP was considered difficult as they were too brisk and there was a lack of understanding about

teenage health issues. As was also reported by Klein and colleagues (2003) young people were concerned about 'community confidentiality' highlighting their concern about being seen by someone they knew.

In summary, current research shows that young people consider primary care to be difficult to access, are concerned about a lack of respect and confidentiality and are often embarrassed about seeking help from primary care for their health problems. Although they provide important findings, these studies have not focussed on young people's views regarding primary care for mental health problems. In addition, the use of surveys to investigate lay views carried with it a number of methodological limitations which will be discussed in the next section.

### ***Methodological limitations of survey studies***

With the exception of Biddle and colleagues (2004) none of the survey studies reported on the characteristics of the non-responders. In the study by Biddle and colleagues (2004) those that did not respond were more like to be male, older, and living in socio-economically deprived areas. As young people from these groups are also more likely to be affected by mental health problems it would have been interesting to know whether these groups were represented (or indeed excluded) from the survey studies reviewed above. In addition, a majority of the studies drew their samples from practice records (the exception being Kari and colleagues (1997) and Klein and colleagues (2003) in which both collected data from students within the school setting). With the knowledge that young people are one of the most difficult groups to engage in primary care services, studies that recruit solely from practice registers are limited to representing young people for whom attending the surgery is relatively unproblematic. As young people who are excluded from school are also more likely to be affected by mental health problems, recruiting from educational settings is also likely to under represent youth who are not attending school or college. Because of the importance of including these groups in any sampling strategy, participants should also be recruited from settings such as youth community groups, social services, and youth services.

The use of survey methodology to research young people's views of help seeking means that the factors to be investigated are pre-determined by the choices made by researchers. As a result aspects of importance to participants but not the researchers are missed. By contrast qualitative methods which allow participants to use their own terminology to describe their views about help seeking enables factors that have not yet been considered by the researchers to be explored. One way of using qualitative methods to examine the help seeking process from the standpoint of the individual or patient is through the use of lay explanatory models (Rogers & Pilgrim 2005). Lay beliefs of youth about mental illness



and the role of primary care may provide some insight into why young people often do not seek help for mental health problems. They may also allow a critical examination of the differences between the way clinicians and patients attribute and describe mental health problems (Pill et al. 2001). Explanatory models of young people and practitioners regarding seeking help for mental health problems will be reviewed below.

### ***Qualitative studies of young people's views on seeking help for mental health problems***

In this section, I will review the qualitative literature on young people's views on seeking help for mental health problems. This will illustrate both the common themes as well as the gaps in the research that will be addressed by this thesis.

In an Australian study, Booth and colleagues (2004) conducted focus groups with young people aged 12-17 years both in and out of school about their health concerns, and whether they accessed health services. Those who were out of school either did not attend school at all or attended sporadically had left mainstream education or attended an alternative education programme. They separated the groups by gender and stratified each group by year of study (year 7 or 8 included 12-14 year olds, year 9 or 10 included 14-16 year olds and year 11 included 16-17 year olds). Eighty-one focus groups were completed but they only analysed 51 of these as data saturation had been reached. A thematic analysis was conducted but it did not contain much interpretation of the themes beyond a basic description of the data.

As detailed in table 3, the authors found that young people defined health mainly in physical terms, and only older participants who were also out of school included emotional and psychological aspects of health in their definitions. As in the survey studies, young people often felt embarrassed and ashamed of needing help, and informal sources of help were preferred. The qualitative data however provides an insight into why this may be the case. When asked about service providers, family practitioners they 'knew and trusted' were identified as the most important, followed by youth health services, family practitioners that they did not know (as they felt it may be easier to speak to someone that they did not know) counsellors not based in schools, school staff and adolescent mental health services. Knowledge of services was limited for young people in school but young people that were out of school were more aware of services available. However, they noted that they would not access them unless they were in 'crisis' or had heard positive feedback about the service from their peers. Young people that were out of school were also more likely to have been ordered to attend a service through the Juvenile Justice Service. Therefore they may have had more experience of using services.

Despite the interesting findings, Booth and colleagues (2004) asked young people about seeking help for general health problems. The following three studies specifically centred on young people's views about seeking help for mental health problems.

Chew-Graham and colleagues (2003) conducted interviews with 22 medical students from two universities in the UK about their experiences of seeking help for mental health problems. It was not reported whether participants were asked if they had themselves experienced mental health problems. Rather the focus was on the stress associated with being a medical student. The students reported that they would prefer to seek help from informal sources such as friends and family than seek help from professional services within their University. As found by Booth and colleagues (2004), students associated seeking help with stigmatising attitudes (e.g. shame, embarrassment, and admitting weakness). They were fearful that their help seeking would impact negatively on their careers; and only a minority felt that seeking help would make them more empathetic doctors. Students did not trust the services and were concerned about a lack of confidentiality. As has been shown earlier and will be reported below, concerns about confidentiality are a consistent finding in both survey and qualitative studies on young people's views on seeking help for mental health problems.

Buston (2002) conducted 32 semi-structured interviews with 14-20 year olds diagnosed with a mental illness and still in contact with a psychiatrist in three districts around Glasgow in Scotland. Participants' responses were classified into the following themes: doctor-patient relationship, treatment, the system, and environs of the hospital/clinic. Attitudes towards GPs were mostly reported on within the doctor-patient relationship theme, with GPs again being perceived as dismissive and not taking young people's symptoms seriously. As with the study by Booth and colleagues, participants noted the importance of continuing to see a doctor with whom they had an established relationship. Buston noted however that participants had been selected to take part in the research by their psychiatrists and so they may have been more positive about accessing services than young people who had disengaged with services or not had their needs met.

Two studies conducted by The Mental Health Foundation sought young people's views about their experiences accessing health services for mental health problems (Smith & Leon 2001; Leon 1999). In the first of these, six focus groups were conducted with 12-25 years olds attending a self-harm group at a hospital, an eating disorders clinic, and community centres within a therapeutic setting (Leon 1999). Most but not all the participants had used services for a mental health problem. Young people reported that GPs lack knowledge about mental health problems but were appreciative of GPs that referred them to specialist mental health services. However, the report lacked any detail about how the analysis was conducted.

The second was a mixed method study using questionnaires, interviews and focus groups with 45 young people with experience of mental health problems (Smith & Leon 2001). As also reported by Buston (2002), many of the respondents felt that GPs were dismissive. In this study, young people were recruited through the professionals they were in contact with, but no further details were given regarding the recruitment. This selection bias leads to the same methodological limitation as noted earlier by Buston (2002).

Despite a number of limitations in the studies by Buston (2002), Leon (1991) and Smith and Leon (2001) there is some consistency in their findings. However, the focus of these studies was on experiences of mental health services rather than primary care. There is a key difference in primary care provision compared to other health services, in that at this stage it is a place where youths can seek help on their own, without needing a referral from another agency or health professional. Given the responsibility that this places on the individual, or in some cases on their carer or parent, this is a crucial differentiator within the help seeking process. Nonetheless, as the review by Horwitz et al (2002) showed, and as noted here, there is a paucity of studies regarding the role of primary care for young adults with mental health problems.

**Table 3: Lay explanatory models of young people**

<b>Authors</b>	<b>Design</b>	<b>Sample</b>	<b>Issues that deterred or encouraged help seeking</b>	<b>Limitations</b>
Booth et al (2004)	Focus groups	Young people in school and out of school	<p>Informal sources of help preferred.</p> <p>Confidentiality, embarrassment, cost, fear of being judged, and the belief that family practitioners not trained in anything other than physical health. A trusting relationship with a FP was considered important.</p>	Thematic analysis very basic e.g. themes were descriptive without much interpretation.
Chew-Graham et al (2003)	Interviews	Medical students	<p>Informal sources of help preferred.</p> <p>Perceived stigma, lack of confidentiality, lack of knowledge about existing services.</p>	Data analysis did not take account of different cultural groups.
Buston (2002)	Interviews	Young people with a diagnosis of a mental health problem for a year or more ago	<p>GPs seen as being dismissive and not taking young peoples' symptoms seriously.</p> <p>Participants noted the importance of continuing to see a doctor with whom they had an established relationship.</p>	Recruited through professionals - selection bias.
Leon (1999)	Focus groups	With and without with experience of mental health problems	<p>GPs lack knowledge about mental health problems but were appreciative of GPs that referred them to specialist mental health services.</p>	No detail about data analysis. Did not investigate how ethnicity may have impacted on experiences.
Smith (2001)	questionnaires, interviews, and focus groups	Young people with experience of mental health problems	<p>GPs lacked understanding and were reluctant to provide certain kinds of support.</p>	Recruited through professionals - selection bias.

### ***Young people's views on primary care for mental health problems***

Two studies specifically explored the role of primary care in youth mental health problems. Biddle and colleagues (2006) conducted interviews with 16-24 year old GHQ 'cases' about their perceptions of GPs as a source of help for mental health problems. They reported the following results:

- GPs primarily deal with physical illness.
- A GPs response to being consulted on mental health issues would be to prescribe medication.
- GPs lacked training in mental health. A view also supported by Leon (1999).
- GPs were unable to provide talking therapies.
- GPs would be dismissive towards someone consulting with mental distress. This is a common theme regarding GPs in the literature and was also reported by Buston (2002), Smith and Leon (2001) and Leon (1999).
- A minority reported positive experiences with their GP such as giving a referral, medication and being supportive.

In a continuation of the 2006 study, Biddle and colleagues (2007) suggest that non-help seeking can be explained by the 'cycle of avoidance' which consists of the following components: young people negotiate 'real' distress and distinguish it from a passing phase; normalisation and coping; and the anticipation of negative consequences such as stigma and changes in identity as a result of seeking help. The authors argue that the model has been developed through a dynamic approach to help-seeking whereby the traditional deterministic theories regarding help-seeking are challenged. However, the authors still consider help seeking to be the ultimate aim. It could be argued that not seeking help is in fact a chosen strategy or a preference and not 'avoidance'. By choosing not to seek help young people may be empowered and in control of managing their symptoms.

### ***Conclusions***

These studies show that young people consider GPs to lack knowledge of mental health problems and are fearful that GPs will be dismissive of a young person seeking help for a mental health problem. Leon (1999) and Biddle and colleagues (2006) also showed that young people appreciate being referred by their GP. Buston (2002) and Booth and colleagues (2004) found that young people valued seeing a GP with whom they had a trusting relationship. Booth and colleagues (2004) also found that young people may prefer to consult a GP that they do not know as it may be easier to discuss health concerns and there may be less concern about parents being informed.

This literature review has shown that young people from ethnic minority groups are least likely to access primary care for mental health problems. In addition, explanatory models of illness in patients with schizophrenia have been found to differ by ethnicity and are associated with patient satisfaction and relationships with clinicians. McCabe and Priebe (2004) found that Whites associated the cause of their illness to biological factors and African-Caribbean and Bangladeshis were more likely to ascribe their symptoms to supernatural and social causes. They also found that biological explanations were associated with enhanced treatment satisfaction and therapeutic relationships. However, a major limitation of most of these studies reviewed above is the lack of detail about how ethnicity impacted upon the views of young people. Leon (1991) included two ethnic minority focus groups but did not analyse differences between these and other groups in the sample. Booth and colleagues (2004) reported that there were differences between 'certain ethnic groups' although further details were not reported. This thesis aims to address this gap by exploring the views of young people from a wide range of backgrounds including African-Caribbean men, Asian females and homeless young people.

Young homeless people report good use of services targeted specifically for them but find that access to statutory health services problematic (Reid & Klee 1999) and subsequently use them less (De Rosa et al. 1999). Young homeless people with mental health problems are concerned about being labelled by providers and feel that they lack control of their assessment and treatment decisions (Darbyshire et al. 2006). As such they are an important group to include when exploring young people's views about seeking help for mental health problems from primary care. However, none of the studies reviewed above included homeless youth.

One of the criteria for assessing quality in qualitative studies is the extent to which the researchers have been reflexive about their assumptions, biases and motivation for conducting a study. Interestingly this was reported in none of the studies reviewed. Yet our previous experiences have an impact upon the way data is collected and interpreted and so, for example, researchers with experience of seeking help for a mental health problem may ask different questions and have alternative understandings of the responses than those without (Rose et al. 2006). Investigating young people's views about seeking help from a GP for a mental health problem has not been done by involving young people with experience of doing so in data collection and analysis. This aim of this thesis is to use a novel methodological approach by involving young service users as co-researchers.

### ***Adults' views of primary care as a source of help for mental health problems***

There are a number of studies about patients' views on primary care that have not focussed on young people, but on a wide age range. Kadam and colleagues (2001) found that people with anxiety and depression had a variety of opinions about the role of their GP. Some felt that their GP would be willing to listen and refer on to a counsellor. Others felt that GPs were too busy and that their problem was too trivial to bother their GP with. Patients also felt that when they wanted it help should be forthcoming immediately, and were not satisfied with having to wait for a few days. Although some patients were positive about medication as a short-term option, many did not consider it to be an effective response to their distress.

Gask and colleagues (2003) found that people with depression had had a range of different experiences with their GP. Some felt that the care they had received was good and when this occurred it was associated with being listened to and understood by their GP. Others felt that their time with the GP was too short or that they had received poor care such as not being able to see a counsellor due to long waiting lists. Communication was found to be an important aspect of patients' perceptions of their care. As reported by Kadam and colleagues (2001), deference played a part for some, with the notion of it "not being right to take up the doctor's time" with their problems.

For Rogers and colleagues (2001), seeking help from the GP was found to be embedded within the context of identity of the person experiencing depression. Contact with the GP is described as being 'negotiated' in that the person makes a decision to seek help based on an inability to cope or experiencing distressing symptoms. Again, as with Kadam and colleagues (2001) and Gask and colleagues (2003), people with depression often questioned whether contacting the GP was a legitimate thing to do.

Chew-Graham and colleagues (2002) conducted a qualitative study on the views of Asian women with regard to psychological distress, self-harm and help seeking. They recruited Asian women from four existing community groups (two for women aged 16-33 years and two for women aged 25-55 years). Participants reported a lack of trust of GPs because they were White and did not understand the cultural expectations placed upon Asian women. At the same time, the women were particularly concerned that Asian GPs might well not respect their confidentiality, which led to feelings of isolation. The study highlighted the unique issues of Asian women facing and managing the community stigma associated with seeking help, something not found in research that isn't focussed on ethnic differences.

Pill and colleagues (2001) conducted 20 focus groups across both rural and urban regions in Wales. Some of the participants had sought professional help for a common mental

health problem. The sample was stratified by sex and age, including groups aged 18-25, 35-45 and 55-70 with a deliberate effort to recruit participants from different cultural backgrounds. As found in the previous studies referred to above, the respondents again questioned whether emotional distress was a legitimate illness for which one should consult a GP and that GPs were unable to offer sufficient time to deal with their problems and “the real causes of depression.” In addition, participants felt that GPs would only be able to provide medication. Although the authors noted that their intention was not to provide full details of their findings, but simply to illustrate the importance of lay views, it would have been useful to know whether their findings differed by age and ethnicity.

As with the literature on young people’s views, these studies reveal a common set of themes but, with the exception of Chew-Graham and colleagues (2002) which focussed on Asian women, almost all did not specifically report upon the views vulnerable groups from ethnic minorities or the homeless.

More recently commentators have focussed on the views of hard to reach groups which include Black and ethnic minorities and the homeless. They have used the concepts of candidacy and recursivity (referred to on page 35) to investigate access to primary care for mental health problems for hard to reach groups. Kovandzic and colleagues (2011) identified that candidacy works in two ways; individuals assess their own eligibility and also the qualifications and ability of a health service to meet their needs. As reported by Kadam and colleagues (2001) and Gask and colleagues (2003) people did not consider themselves eligible for healthcare as their symptoms were not worthy of medical attention. Individuals felt that practitioners did not express sufficient knowledge about mental health problems to convince patients that they could be helpful. Lamb and colleagues (2011) found that hard to reach groups (which also included adolescents with eating disorders) considered their mental health problems to be caused by social problems but that this was not shared or understood by practitioners. In turn patients were reluctant to adopt professional understanding of ill health as to do so would be seen as a threat to their identity. This dissonance led to communication problems in the consultation because practitioners were unable to or unwilling to adapt to patients beliefs and the way they presented their problems.

### ***Primary care practitioner views of young people***

In addition to lay views on primary care, it is important to understand the views of the primary care practitioners about managing youth mental health problems. This can help us define the issues faced by practitioners and how they can be addressed in order to improve services for young people.



Jacobson and colleagues (2001) conducted interviews with 40 primary care staff consisting of GPs, nurses and receptionists. They found that all the primary care professionals were aware that young people were concerned about confidentiality. Nurses were aware that they may be seen as mother figures and felt more able to communicate with young people than GPs and receptionists. GPs felt that young people were a difficult group to manage and held both positive views (young people as rational) and negative views (they indulge in risky behaviour for which they need primary care) about providing care for young people. Information about available services was considered insufficient by GPs. Nurses, receptionists and some GPs identified training needs in communication skills. Although there was no specific mention of mental health problems, some GPs felt they would benefit from training in counselling skills. GPs felt that good communication occurred when young people were respectful and listened, indicating a paternalistic approach to managing young people. GPs agreed that young people would benefit from more information and education about general practice services and confidentiality. Overall the study revealed GPs awareness of the barriers faced by young people together with the need to improve their own skills.

In an Australian study, Kang and colleagues (2003) conducted focus groups and interviews with GPs, community health centre staff and youth health services staff to ascertain their views about providing primary care for young people. They found that GPs felt that youth health care for young people was affected by structural barriers such as time and funding, and a need for different settings such as drop-in centres or school-based services. Problems communicating with and confidence in working with young people were also concerns for GPs as was the need to improve cross agency working with mental health services. Community health workers had similar concerns around feeling comfortable working with young people, negotiating confidentiality, issues with funding, having appropriate settings for young people to be seen in, and poor supportive networks across relevant agencies. By contrast, youth health workers were relatively confident working with young people and felt that young people had good access to their services. However they considered themselves isolated from mainstream health services, experienced funding constraints and were overwhelmed by the complexity of their caseloads.

The findings of both Jacobson and colleagues (2001) and Kang and colleagues (2003) illustrate that there are differences between primary care professional groups working with young people's health problems. Nurses and youth health workers were more confident than GPs, receptionists and community health workers. This may be because the former work regularly with younger age groups and are therefore more experienced and confident in communicating with young people.

In another Australian study, Bernard and colleagues (2004) compared the findings from Booth and colleagues (described above) to that of focus groups with service providers (GPs, community health centre staff, and youth health workers). They found that young people and service providers agreed on many aspects of access to health care such as improving collaboration with other providers and having well-publicised services. However, as reported by Kang and colleagues (2003), service providers also cited structural issues, such as opening hours as perceived barriers to youth accessing health care. Although service providers recognised the need to promote and ensure confidentiality they did not mirror youth perspectives on service delivery, such as the importance of hearing experiences of others and the role of school based services. The gap between youth and service providers' views about barriers to accessing health care suggests that these two groups consider different aspects of care provision to be important. An understanding of how primary care can be improved from the perspectives of young people, and an examination of providers' responses to such quality improvements is needed to close the gap in perspectives between the two groups.

### ***Practitioner views on managing mental health problems***

The studies referred to above took a broad approach to youth health and did not focus specifically on mental health problems. The following studies focus on practitioner views about managing mental health problems. However a majority of this literature in the UK focuses on the views of GPs regarding adult patients.

Sigel and Leiper (2004) interviewed 10 GPs and conducted a grounded theory analysis. They argued that GP management of mental health problems could be conceptualised through a series of five interconnecting domains:

- Exploring psychological problems through a holistic approach to the patient.
- Attempting to contain a patients' mental health within the realm of their general health.
- Their views about psychological problems and treatments.
- Interactions with specialists.
- Referral decisions.

They concluded that GPs felt that communication with specialists is problematic; access to talking therapies and other services was lacking, and that assessment tools and formal procedures close down communication.

May and colleagues (2004) conducted a secondary analysis of GPs accounts of managing chronic illness in primary care. They found that GPs felt that their patients agreed with their approach to depression as a psychological rather than biomedical condition. GPs felt that depression should be managed in primary care unless symptoms were very severe and, as found by Sigel and Leiper (2004), noted the lack of resources for referral. The authors argue that for depression, there is congruence between patients and doctors views which allows them to negotiate and agree upon treatments. However, it would have been interesting if this claim had been substantiated by an analysis of patients' accounts and had not only relied on GPs views.

Rogers and colleagues (2001) found that GPs constructed their accounts of managing depression in terms of clinical symptoms although they acknowledged the contribution of social factors. As reported by Sigel and Leiper (2004), GPs felt that the lack of resources for referral to secondary care was a major barrier to providing quality care.

Chew-Graham and colleagues (2002) conducted semi-structured interviews with GPs from inner-city, suburban and semi-rural practices to investigate their views on managing depression in primary care. They found three different types of explanations for dealing with depressed patients. Firstly depression was a normal (but medicalised) response to

every day life; secondly, it was also felt that a diagnosis of depression was beneficial to the patient and often for the practitioners as well; and finally consultations with depressed patients were difficult due to lack of resources and the demanding nature of depressed patients.

Dew and colleagues (2005) conducted focus groups with GPs in New Zealand and found that managing mental health problems was affected by problematic relationships between primary and secondary care services, a focus on physical symptoms and the acknowledgement that patients are resistant to seeking help due to stigma and a culture of self-reliance. They also found that GPs felt they had tacit skills which enabled them to do mental health work and advocated the importance of communication skills during the consultation.

These studies illustrate that GPs consider the quality of primary care for people with mental health problems to be affected by resource issues, access to primary care services and problems interfacing with specialist mental health professionals. GPs focussed on the importance of interpersonal aspects of care although it was acknowledged that consultations with patients can be difficult for both GPs and psychiatrists. The importance of approaching mental health problems from a patient-centred perspective was also a common theme in qualitative primary care studies. Although these studies focussed on managing mental health problems in primary care, they lacked detail about younger age groups.

This review has found only one qualitative study of primary care practitioners' (PCPs) views on youth mental health problems. In a US study, Richardson and colleagues (2007) conducted focus groups with 32 paediatricians and three paediatric nurse practitioners on their beliefs concerning barriers to treating adolescent depression. They found that providers adopted different roles according to their attitude to prescribing anti-depressants. Practitioners were more motivated to prescribe anti-depressants if they considered it as a first-step in treatment. Those that were less motivated felt their role was a 'stop-gap measure', particularly in areas where there was a long waiting list for mental health specialist care. Providers who advocated that counselling was more beneficial than medication felt they were the 'coordinators of care'. As found in the adult studies reviewed above, other PCP concerns were poor communication with mental health specialists and access to counselling. The effect of a recent FDA warning on prescribing anti-depressants to adolescents manifested itself as a fear of litigation and media attention. A limitation of this study is that despite using three researchers to code the data, neither areas of agreement or dissent were reported as part of the analysis. As a result it was not clear whether group norms or disagreements were formed regarding different roles, and if group interaction had an impact upon theme development. For example, it was not reported

whether there was more consensus about a particular role and less agreement about another. Nevertheless, this study provides some understanding of the manner in which primary care providers manage young people, and how the barriers to treatment are negotiated by PCPs.

Most studies have asked practitioners or young people for their views about managing youth mental health problems. Jorm and colleagues (2008) conducted a telephone survey of clinician, youth and parental beliefs about interventions for depression and anxiety in young people. The clinician sample consisted of GPs, psychiatrists, mental health nurses and psychologists. Clinicians agreed that GPs and mental health professionals, CBT, counselling, reducing substance use, physical activity, relaxation training and medication would be helpful. Mental health specialists were more likely to recommend another mental health professional rather than a GP as a source of help but the study did not report which profession GPs were most likely to recommend. Clinicians agreed that antidepressants would be a useful source of help however, young people and their parents rated informal sources of help as more useful than antidepressants. There may have been differences between the views of the young people and their parents but this was not reported by the authors. Nevertheless, this study provides further evidence that there are substantial differences between the views of clinicians and young people and their parents about how to manage mental health problems.

Although several studies identify a gap between the views of practitioners and young people regarding the management of mental health problems, no studies have been found that address practitioners' views of those aspects of primary care that have been specifically identified as important by young people. This is an important gap in the literature because, as discussed earlier, young people's views about their mental health problem have been shown to have an impact upon the outcome of a consultation. In addition, if primary care practitioners are more aware of the concerns of young people, this may go some way towards improving the quality of care they provide.

## Quality improvement in primary care mental health

There has been an increased focus on improving quality of health care in the UK (Department of Health 2010). This has been guided by a number of national initiatives that have had a significant impact upon the delivery of health care in England. The National Service Framework (NSF) for Mental Health was developed to improve the quality of care for people with mental health problems aged 18 to 65 years old (see box 1). Young people aged less than 18 years are covered by the NSF for young people, children and maternity services which will be reviewed in the following section.

### **Box 1: National Service Framework for Mental Health - adults**

- **set** by the National Institute for Clinical Excellence and National Service Frameworks
- **delivered** by clinical governance, underpinned by professional self-regulation and lifelong learning
- **monitored** by the Commission for Health Improvement, the new National Performance Assessment Framework, and the National Survey of Patients.

### **The National Service Framework for Mental Health - Standards two and three Primary care and access to services**

#### **Aim**

To deliver better primary mental health care, and to ensure consistent advice and help for people with mental health needs, including primary care services for individuals with severe mental illness.

#### **Standard two**

**Any service user who contacts their primary health care team with a common mental health problem should:**

- **have their mental health needs identified and assessed**
- **be offered effective treatments, including referral to specialist services for further assessment, treatment and care if they require it.**

Although hailed as a great success, the NSF has recently been superseded after 10 years by 'New Horizons' (Department of Health 2009) which is focussed on the role of CAMHs rather than primary care. The only reference to primary care is in an acknowledgment that GPs and other primary care staff have mental health training needs. As the New Horizons programme is still being developed, I will focus on the NSF standards as they still form part of quality improvement in the NHS.

## ***The Quality and Outcomes Framework***

Primary care practitioners are rewarded for quality through an incentive scheme called the Quality and Outcomes Framework (QoF) outlined below (Majeed et al. 2007). Although the patient experience domain of the QoF assesses length of consultation and access to a GP or practice nurse through patient surveys, these QoF indicators do not apply to young people under the age of 18. Moreover, it is not clear whether patient surveys have the potential to capture the diversity of patient experiences and how they can be best incorporated into the planning and development of services (Campbell et al 2007). Previously, practitioners were awarded QoF points for reflecting upon, proposing and making changes to their services based on the results of the patient experience survey (NHS Employers and General Practitioners Committee 2004). However, the 2009 version of the QoF has removed this element although points are now rewarded for the patient access results of the patient survey (NHS Employers & General Practitioners Committee 2009).

### **Box 2: The Quality and Outcomes Framework (QoF)**

Mental health was previously represented in the QoF by having a severe mental illness register and conducting annual physical health checks. There is also provision for checking lithium levels of patients with bipolar illness and having a register and annual checks for people with dementia.

Depression has recently been added in the last few years and this includes screening at risk patients, testing for severity and following the patient up between weeks 5 and 12 after diagnosis and treatment.

#### **Patient experience domain**

Assesses the following characteristics: environment and helpfulness of reception staff; Getting through on the Phone; Accessing GP appointments; Patient satisfaction with practice opening hours; Consultations with healthcare professionals; Patient satisfaction with overall care and planning care and Accessing local out of hours care.

### ***Definitions of quality improvement***

A wide range of different terms are used to describe quality improvement. These are defined below. Although they are often used interchangeably it is important to demarcate the boundaries between the meanings of each in order to understand how they can impact upon practice.

Guideline – Systematically developed statements to help practitioners make decisions in specific clinical circumstances (Grimshaw & Russell 1993).

Indicator – A measureable element of practice performance for which there is evidence or consensus that it can be used to assess both the quality and change in the quality of care provided (Campbell et al. 2000; Lawrence & Olsen 1997). An “indicator” represents the benchmark of quality of care (Herman et al. 2006).

Standard – The level of compliance with an indicator (Lawrence & Olsen 1997). This could be a target standard which has been set prospectively or an achieved standard which is measured retrospectively (Campbell et al. 2003).

### ***A focus on quality indicators***

The NSF has been implemented through a combination of clinical guidelines and quality assessment, underpinned by professional self-regulation and lifelong learning. One way of assessing the quality of care provided is through quality indicators.

Shield and colleagues (2003) developed quality indicators for primary care mental health. Eleven different stakeholder groups were recruited to take part including, GPs, clinical psychologists, commissioners, counsellors, nurses (practice, district and health visitor), psychiatrists, social workers, carers, patients and people working in the voluntary sector. The age groups were not reported so I have assumed that the stakeholders were adults aged 18 and over. The quality indicators were developed from existing quality statements, standards including the National Service Framework for Mental Health, grey literature from key stakeholder groups and focus groups with patients. Participants were asked to rate an initial set of 334 indicators using the Delphi process. Consensus was calculated and reported back to participants who conducted a second round of rating. Although 97% of the indicators were considered to be valid by one or more panels, rating between panels differed significantly and only 26% were rated valid by all panels. These are summarised in table 4.



These findings show that what is considered high quality care differs according to specific groups. For example, patients, carers and voluntary sector workers felt it was valid to have emergency home visits and more practice nurse involvement in the primary care of people with mental health problems but these aspects of care were not rated as valid by health professionals (e.g. GPs and psychiatrists). In addition, patients and carers rated a higher number of indicators as valid than did GPs. Because young people were not specifically included in the sample the quality indicators developed by Shield and colleagues may not address aspects of care that are considered important by young people with mental health problems.

**Table 4: Quality indicators for primary care mental health developed by Shield and colleagues (2003)**

Quality indicator (number of indicators)	Example
Practice level	
Access (4)	A member of the primary health care team is available as a point of contact for all patients to talk to in an emergency
Practice policies (5)	There is an agreed definition of severe and enduring mental illness which is explicit and standard within the practice
Information for patients and carers (2)	Patients are given information about their condition, treatments, medication (including side effects) and coping strategies
Medical records (3)	Details of currently prescribed maintenance drugs are prominently recorded in the medical records
Patient staff relations (11)	Physical symptoms in people with mental health problems are taken seriously and not automatically considered as psychosomatic
Confidentiality and consent (3)	Where practicable, patient consent is sought before giving information to carers
Comprehensive assessments (2)	Assessment of physical, psychological, and social health needs in patients with mental health problems includes an assessment of risk
Patient involvement in treatment plans (5)	Patients are as fully involved as practicable in the formulation and delivery of their care (e.g. through the use of self-care plans)
Psychotropic prescribing (7)	Prescribed medication is at the minimum necessary dosage
Psychological treatment (3)	Counsellors, psychotherapists, and other practitioners of talking treatments working within practices have regular supervision
Follow up (3)	Patients with a diagnosis of mental illness are offered regular appointments to monitor and follow up treatment, symptoms, side effects and adherence
Higher level (primary care group/trust and health authority) indicators	
Registration with a general practice (1)	There is a written protocol/strategy to ensure that specific difficult to place groups are not excluded from registration with general practices (e.g. homeless, drug misusers, residential care residents)
Equity of access (5)	including talking treatments) are available to all practices

**Table 4: Quality indicators for primary care mental health developed by Shield and colleagues continued (2003)**

Quality indicator (number of indicators)	Example
Referrals (2)	There is a single point of rapid access for urgent referrals to specialist mental health services (duty professional or fast tracking service)
Psychotropic prescribing (2)	There are locally agreed written protocols for prescribing across the primary-secondary care interface including hospital initiated prescribing
Comprehensive range of good quality mental health services (3)	A range of services is available, including talking treatments
Mental health promotion (2)	Procedures exist which demonstrate a commitment to promoting the mental health of all individuals and communities
Out of hours care( 3)	There are locally agreed written standards and protocols for the delivery of out of hours care for mental health problems
Training and development (9)	There is a demonstrable commitment to promote continuous professional and practice development in primary care
Effective partnerships between health authorities, local authorities and primary care groups/trusts (1)	There is a range of collaborative initiatives in place with other key agencies demonstrating effective partnerships (local authorities, voluntary agencies, other primary care groups/trusts)
Monitoring (3)	There are written protocols and mechanisms in place for monitoring prescribing of psychotropic drugs

### **Youth specific national initiatives**

A number of national initiatives have developed quality indicators and standards for youth healthcare (summarised in table 5). The 1999 National Service Framework (NSF) for Children, Young People and Maternity Services states that all staff working with children and young people with mental health problems should provide appropriate interventions and specialist referral when problems are identified (Department of Health, 2004). This initiative was aimed at 0-18 year olds and covered 11 different standards of which standard 3 and 9 are of particular importance to this thesis (see Box 3 below).

**Box 3: National Service Framework for Children, Young People and Maternity Services**

Standard 1 Promoting Health and Well-being, Identifying Needs and Intervening Early

Standard 2 Supporting Parenting

**Standard 3 Child, Young Person and Family-centred Services**

Standard 4 Growing Up into Adulthood

Standard 5 Safeguarding and Promoting the Welfare of Children and Young People

Standard 6 Children and Young People who are Ill

Standard 7 Children and Young People in Hospital

Standard 8 Disabled Children and Young People and those with Complex Health Needs

**Standard 9 The Mental Health and Psychological Well-being of Children and Young People**

Standard 10 Medicines for Children and Young People

Standard 11 Maternity Services

**Table 5: Quality improvement initiatives for youth in primary care**

Quality initiative/ Quality indicator with example	You're welcome standards (Department of Health, 2007)	Getting it right for teenagers in your practice (Royal College of General Practitioners 2002)	Bridging the Gaps – healthcare for adolescents (Royal College of Paediatrics and Child Health 2003)	National Service framework for children, young people and maternity services – Standard 3 and 9 (Department of Health 2004a)
<b>Access to services</b>	In a non-specialist service there are opportunities for self-referral, and clear lines of referral to specialist services as required.	Do you have a special appointment system for emergency contraception?	Primary care services for young people should: be based on a mapping of service need for young people within defined areas and be readily accessed geographically and by times of availability.	Any service user who contacts their primary health care team with a common mental health problem should: <ul style="list-style-type: none"> <li>• have their mental health needs identified and assessed.</li> <li>• be offered effective treatments, including referral to specialist services for further assessment, treatment and care if they require it.</li> </ul>
<b>Advertising and information</b>	The service publicity material makes clear: <ul style="list-style-type: none"> <li>• young people's entitlement to a confidential service, including any limitations to confidentiality</li> </ul>	Have a special practice information booklet for teenagers.	Primary care services for young people should be well advertised with confirmation of their confidentiality.	Primary Care Trusts and Local Authorities ensure that information is provided in each locality which explains how to seek advice and gain access to specialist services as necessary.
<b>Confidentiality</b>	Confidentiality and consent policies makes clear young people's entitlement to confidentiality and any limitations to confidentiality with regard to child protection.	Get every practice team member to sign up to the practice confidentiality policy...reassure young people about confidentiality in consultations.	Issues surrounding the question of confidentiality when sharing information between services for the benefit of young people need to carefully examined, and the use of adolescent held health records further developed.	All health services develop policies which take account of the needs of young people, and include addressing issues of confidentiality, copying young people in to clinical correspondence or writing to the young person; and wherever possible, by the holding of personal health records by young people.
<b>Training</b>	Appropriate staff members receive training and relevant clinical appraisal to ensure that they are competent to: <ul style="list-style-type: none"> <li>• discuss necessary and relevant health issues with young people</li> <li>• make appropriate referrals when necessary, and</li> <li>• manage difficult consultations.</li> </ul>	Make sure that all team members are skilled in communicating effectively with young people.	Relevant members of the primary health care team, (from senior GP partner to receptionist) should consider additional training in adolescent health and communication with young people.	All staff working with children and young people receive training and are skilled in the Common core of skills, knowledge and competencies set out in this standard which enable them to communicate with children and young people and their parents, and assist them to achieve their full potential.

The Department of Health has published You're Welcome Quality Criteria. It is targeted at commissioners and providers of health services and supports standard 3 of the NSF for children and young people (Department of Health 2007). The criteria are based on examples of effective local practice but the report does not explain how the criteria were developed, or if and how young people were involved. The Royal College of General Practitioners set up a working party on adolescent health which published a report entitled 'Getting it right for teenagers' to provide guidance on how to make GP practices youth friendly (Royal College of General Practitioners & Royal College of Nursing 2002) .

A report entitled 'Bridging the Gaps' (Royal College of Psychiatrists, 2003) was developed in partnership with a number of Royal Colleges' charities and the Department of Health. The report gave recommendations to commissioners and planners for ways of developing and implementing adolescent friendly health services as well as identifying training needs of professionals. It was developed through a series of seminars, examples of good practice and evidence base from literature. The consultation process involved inviting comments on the draft report from a wide range of stakeholders including consumer groups and service user organisations, but ultimately it was not clear which groups were invited to comment or what level of response was achieved. The final report provided both recommendations about adolescent health care in general (from community to tertiary services) and primary care specifically (see table 5).

All four reports stated that training, access, informing young people and ensuring confidentiality were important features of quality of care for young people although the extent to which these were the responsibility of primary care was less clearly defined. This may have been because a majority of the reports applied to the healthcare service in general and did not focus specifically on the role of primary care. None of the four quality initiatives reported that young people were involved in developing the standards, other than that consumer organisations had been invited to comment on draft reports. Only one report (NSF standard 9) focussed specifically on mental health while all the others referred to services for general health problems. When focussing on mental health, references were made to the role of CAMHs and not primary care.

Service standards for young people's mental health have been developed for use in multi-agency CAMHs in the UK (shown in table 6). Although the standards are comprehensive, the self-review process used by CAMHs for assessment does not incorporate each of the service standards and corresponding criteria (Royal College of Psychiatrists 2006). Self-review consists of a one-page form which assesses indicators of activity, resources and outcome. These consist of 19 questions about general through-put, referrals, staff recruitment and retention. For example, 'how many cases were referred to in-patient CAMHS in last 6 months?' As in the youth health initiatives above, young people were

apparently consulted as part of the development process but no further details were given on how this consultation was undertaken.

Although these standards refer to youth mental health specifically, only a minority are applicable to primary care, such as explaining the limits of confidentiality and encouraging the continuing professional development of staff. Most of the standards refer to the processes normally undertaken by specialist teams, for example, arrangements for leaving the service and multi-agency working between specialist CAMHs teams and other sectors. As a result, as far as I can ascertain there are no quality indicators for youth mental health that have been specifically developed for use in primary care.

**Table 6: Example of service standards developed by the Quality Improvement Network for Multi-agency CAMHS (Royal College of Psychiatrists, 2006)**

Topic	Standard	Criteria
Referral and Access	Young people are fully involved and informed during the referral process and know what to expect	Appointment letters for assessments explain who young people and parents will be seen by, where they will be seen and what the purpose of the assessment is
Environment and facilities	The locations where Specialist CAMHS are delivered are well-designed and have the necessary facilities to meet service needs	Specialist CAMH centres are age-appropriate and young person-friendly
Information and consent and confidentiality	Young people and their parents or carers are well-informed about their rights to information and confidentiality and the limits of these rights	Young people who are assessed as having capacity are asked to give or withhold consent before case material is disclosed to their parents
Care and intervention	Young people have a comprehensive and effective range of interventions available to them, delivered by qualified and informed practitioners	Young people are treated by practitioners who are trained to work with young people, or who are receiving adequate supervision from a professional with this training
Rights, Safeguards and Child Protection	The rights and individual needs of young people and their families are recognised and responded to, regardless of their gender, ethnicity, religion, ability, culture, or sexuality	The specific needs of young people and parents from different ethnic, cultural or religious backgrounds are respected and responded to
Transitions	Young people and their parents are involved in agreeing arrangements for leaving the service and know how to re-access help when they need it	On leaving the service, staff tell young people and parents how they can get back in touch if they need help
Enabling Frontline Staff	Staff are well-trained for their jobs, and their continuing professional development is facilitated	Training needs are informed by an annual review of the skills needed within the service
Multi-Agency Working	Staff engage in activities and initiatives to improve joint working	There is regular dialogue about the needs of local young people and their families between generic workers from all sectors, and Specialist mental health agencies
Commissioning	Commissioners ensure that services are provided for young people who have complex needs or who belong to specific at risk or need groups	Commissioners ensure that services are provided for young people with mental disorders who have particular needs as a consequence of being members of minority ethnic group



## **Quality improvement for primary care youth health: intervention studies**

Moving on from initiatives that have been developed by organisations to improve the quality of healthcare delivered to young people, I will now review individual studies that illustrate which interventions are successful in improving quality of youth health in primary care.

An educational intervention for Australian GPs in adolescent health has been shown to produce improvements in knowledge, skill, self perceived competency, satisfaction with the programme, and self-reported change in practice (Sanci et al 2000). However, Sanci and colleagues (2000) found that the objective ratings of rapport by standardised adolescent patients at seven month follow-up did not improve. All outcomes except for the confidentiality ratings (which deteriorated) were sustained at the 13-month follow up (Sanci et al. 2005). This brings the overall usefulness of the findings into question because of the importance of confidentiality for young people's help seeking. Assurances of confidentiality have been shown to increase young peoples' willingness to disclose sensitive information about substance use and mental health problems and seek help (Ford et al, 1997).

Bower and colleagues (2001) reviewed preliminary evidence that treatments by specialist staff and educational interventions were effective in adolescent primary care mental health but concluded that the evidence base consisted of studies of questionable quality and contained few rigorous evaluations. A recent pilot training programme to improve GP detection and recognition of depression in children and young people proved largely unsuccessful (Gledhill et al. 2003).

GP registrars have been successfully trained in this area and although they were shown to improve their knowledge and skills they were not followed up to see how this translated into everyday practice (Bernard et al. 1999). In an Australian study, Pfaff and colleagues found that a one-day GP training course improved detection rates of psychological distress in young people but that this did not lead to changes in patient management (Pfaff et al. 2001) . These findings are similar to studies with adults which have reported that educational programmes for primary care practitioners fail to improve clinical outcomes for depressed adults (Thompson et al. 2000) which suggest that training interventions alone are insufficient to result in improved clinical outcomes.

Other studies have reported improved mental health outcomes for young people. Walker and colleagues (2002) invited teenagers to discuss health concerns with a practice nurse and develop plans for healthier lifestyles. They found that more intervention group participants had a reduced likelihood of being depressed and reported a positive health-

behaviour change (for, diet, exercise, smoking, or drinking alcohol) at 3 months than the control group. This did not, however, persist at 12 months.

A randomised controlled trial in the US found that depressive symptoms were reduced for adolescents with access to psychological therapies and case managers in primary care (Asarnow et al. 2005). A recent follow-up of their original study reported that this reduction did not persist at 18 months (Asarnow et al. 2009). This may indicate that long term improvements in health outcomes require continued support such as ongoing care manager support.

Overall, these studies suggest that interventions which include quality improvement components within training programmes are successful at improving health outcomes in the short-term but such changes require investment in an overall programme of quality improvement. This may be met with some resistance by PCTs because, as highlighted by Bower and colleagues (2001), there is a lack of evidence about the impact of quality improvement initiatives in primary care mental health for young people. One reason may be because quality improvement is often not measured as opposed to quality assessment which requires some type of measurement (Campbell et al. 2002). For example, the quality indicator stating that 'practitioners should be mindful about confidentiality' (Department of Health 2007) is not formally assessed. However, testing for severity of depression is measured through the Quality and Outcomes Framework and as such, forms part of a quality assessment (NHS Employers & General Practitioners Committee 2009).

Similarly the specific aspects of care that are considered important for managing young people's health (as outlined in table 5) are not as yet measured as part of quality assessment which may be because they are considered to be aspirational targets.

### **Quality improvement collaboratives**

One of the ways of implementing quality improvement in practice has been through the development of 'collaboratives'. Quality improvement collaboratives essentially describe a model of quality improvement which brings together experts and peers to exchange best practice and facilitate quality improvement. The key features include (adapted from Øyvretveit et al 2002):

- Participation of multi-professional teams.
- Specific focus on a clinical or administrative topic.
- Topics where there are large variations in care or gaps between best and current practice.
- Participants learn from experts.

- Participants use a change testing model to assess the effect of a planned change – for example the Plan-Do- Study-Act (PDSA) cycle whereby the desired improvement is planned, carried out, the results observed and the lessons learned are acted upon (Institute for Health Care Improvement 2010)
- Teams set targets and track their performance by collecting data.
- Teams meet at least twice for 1-3 days to share experiences and report results.
- Between meetings participants exchange information and can receive support from collaborative organisers.

Although attempting to improve quality of care is a widely accepted strategy in healthcare, the effects of quality improvement collaboratives are uncertain (Schouten et al. 2008). Fletcher and colleagues (2008) established a quality improvement collaborative to facilitate the introduction of Graduate Mental Health Workers (GMHW's) in primary care. GMHW's, their supervisors, representatives from primary care and specialist mental health teams and service user groups took part in at least one of three sessions consisting of skills training, expert speakers, guidance on the role of GMHW's and Plan-Do –Study-Act exercises. They found that participants felt that patients benefited from improved access to support from the GMHW's but it was not possible to show if this actually resulted in improved clinical outcomes. The GMHW's that took part in the collaborative considered it to be useful, felt that their job satisfaction increased and were able to identify problems associated with their role such as inconsistent supervision . Although these findings illustrate that practitioner's benefit from being involved in quality improvement collaboratives, it is not clear whether patients are involved and what the impact is from their perspective.

### **Practitioner views on quality**

Improving quality in primary care in general is problematic (Campbell et al. 2002). As yet, there is no consensus on how to measure quality (i.e. whether the focus should be on health outcomes or processes). In addition, collecting data is time consuming and difficult. Information systems are slowly being set up to enable easier data collection strategies for practices and trusts. There are competing priorities in primary care and as such often other initiatives have begun to take priority (e.g. Quality and Outcomes Framework). Successful quality improvement programmes can be challenging to implement due to resource issues and the threat of being blamed for poor performance (Campbell, et al. 2002). Implementing clinical guidelines can also be difficult because they can limit the discretion of doctors and the autonomy of local commissioners, and can fail to represent widely held views of patients, only reflecting the narrow views of a few clinicians (Haycox, 1999).

Valenstein and colleagues (2004) found that a majority (65%) of mental healthcare providers in the USA felt that feedback about quality indicators would be valuable in efforts

to improve care, however only 38% felt able to influence performance related to the indicators and just 13% were willing to accept incentives coupled with risk. They found that barriers to improving quality of care included competing interests and a lack of resources and incentives. Providers that were more positive about quality assessments were also more likely to perceive themselves as having a greater influence over the indicators and considered there to be fewer barriers to making improvements in care. This supports the notion that the relative success of a quality indicator depends upon the extent to which practitioners believe they have some control over that which they are being assessed (Campbell et al. 2000).

The quality indicators developed by Shield and colleagues (2003) for primary care mental health were developed by a range of stakeholders including practitioners. However, practitioners' views on the usefulness of the Shield indicators and ways that they can be incorporated into practice have not been sought. This is important because practitioners are tasked with implementing quality improvement initiatives.

In the UK, GPs express greater doubt than health authority managers about the validity of quality indicators suggested for use in primary care (Campbell et al. 1998). Dowrick and colleagues (2009) conducted a qualitative study on the views of patients and practitioners regarding the introduction of standardised measures of depression severity for the QoF. GPs acknowledged that although it was a useful tool, it was more applicable for GPs with less experience and confidence in assessing depression. GPs preferred to rely upon their own clinical judgements compared to a standardised measure of severity. Patients were more positive about the measure as it prompted them to present their symptoms in consultation but also acknowledged that GPs may manipulate the measure to avoid the stigma of depression.

These studies illustrate that just as there are differences between the views of patients and health professionals regarding seeking help for mental health problems in primary care, there are also differences between these groups about the usefulness of quality indicators. Patients are more likely to focus on their individual needs e.g. humaneness and communication (Wensing et al. 1994) while managers are concerned with aspects of efficiency and cost-effectiveness (Campbell et al. 2000). Although we know there is a disparity between the groups, we do not know what practitioners think about aspects of quality defined by patients. More specifically, this review has found no studies that have sought primary care practitioners' views on quality indicators that have been developed by young people.

The involvement of patients is now a core component of health services research and quality improvement. This will be reviewed in the next section.

## **Patient involvement in primary care and mental health service research and development**

Patient involvement is a significant feature of health policy through The NHS Plan (Department of Health, 2000), which emphasized the government's commitment to creating a patient-centred NHS. The Department of Health states that the views of patients and carers should be considered in designing, planning, delivering and improving health care services (Department of Health 2005). In addition, the National Service Framework for Children and Young People states that the views of young people and their parents should inform commissioning decisions (Department of Health, 2004). However there is often a disparity between policy and practice. It can be argued that the extent to which patients are meaningfully involved in designing healthcare is heavily influenced by existing differences in status between patients and professionals.

In the most traditional of health professional/ patient interactions, the patient is passive and entirely subordinate, while the "all knowledgeable" health professional sits in judgement, dispensing advice and solutions for the illness presented to them by the patient. Today the passive patient/dominant health professional has generally become moderated, but it is not entirely absent in many relationships. The fundamental tenets of good general practice support a bio-psycho-social approach to illness and consider the patient as an active partner in the consultation (Royal College of General Practitioners, 1972). This is the theory but it is often not the reported experience.

The concept of the expert patient is based on the assumption that 'patient knowledge' about their illness is an untapped resource and can be used to empower patients to be key decision-makers and give them greater responsibility in the treatment process (Department of Health 2001) , representing a substantial shift in power relationships between the patient and the health professional. In addition to the consultation, patients are increasingly becoming involved in service development. Primary care practices are now tasked with forming patient participation groups whereby patients are consulted, and in some cases involved in decisions about quality improvement at the practice level (National Association of Patient Participation 2007).

Giving credence to patient knowledge is an important component of patient-centred practice but qualitative studies in primary care have found that people with mental health problems do not consider themselves as equal partners with health professionals. Lester and colleagues (2006) identified that only a minority of patients with serious mental illness felt able to contribute to decisions about their healthcare because of a lack of practitioners' time or treatment options other than medication, as well as a fear of being perceived as

being difficult. Patients felt that working in primary care would be an effective way of becoming more involved in their healthcare and influencing service delivery for others with similar problems. However, primary care practitioners held negative views about treating people with serious mental health problems and were unwilling to consider a partnership approach to consultations and patient involvement in primary care provision. Campbell and colleagues (2007) found that patients with mild to moderate mental health problems experienced a lack of patient-centred care because their health problems were often managed in a generic way without taking note of individual circumstances. Although positive aspects were identified, quality deficits in both primary, and, more especially, secondary care were noted such as inadequate follow up and poor interpersonal skills.

People with mental health problems have been found to endorse a more paternalistic relationship with their GP compared to other mental health professionals, preferring to be referred to as a patient and addressed by their first name, to address the GP by their last name and for their GP to be formally dressed (McGuire et al. 2003) . These studies suggest that shared decision-making in primary care for people with mental health problems is rare. In addition, interactions between psychiatrists and their patients have also been found to be problematic. McCabe and colleagues (2002) conducted a conversation analysis study of 32 naturalistic psychiatrist-patient interactions and found that although patients were keen to discuss their symptoms, psychiatrists were unwilling to do so and adopted methods (e.g. responding to a question with their own question) to avoid dealing with the concerns put forward by their patients.

Young people have additional factors affecting their position in relation to health professionals:

- Due to their age they may lack the confidence to challenge an adult in a position of authority, let alone a health professional who comes wrapped with all the traditional cultural and historical trappings of 'expertise'.
- As a young person their position as 'consumers' is yet to be fully developed.
- They may have only just begun to exercise their democratic rights through voting (if they vote at all).
- They may only just be developing financial independence in relation to adults.

For these reasons their needs tend to be assessed and defined for them by others – specifically adult health professionals - and as a result they tend to have little influence in the design and delivery of services (Worrall-Davies & Marino-Francis 2008). If these are to become more patient-centred, young people will need to be involved in the development of health services aimed at them.

## Patient surveys

Patient involvement in primary care largely takes the form of patient surveys which are used extensively to monitor and assess performance as laid out by NICE guidelines and the NSF.

The 1998 GP patient survey was one of the first national surveys to collect patients' views in order to improve primary care services. It found that young people aged 18-24 were more critical than older age groups regarding GP knowledge about their condition, lack of time, provision of information and listening skills. A number of patient surveys – but none which reported age difference - found that respect, confidence, trust and continuity of care are considered important aspects of primary care (Roberston et al. 2008; Wensing et al. 1998).

Rao and colleagues (2006) measured correlations between mean practice scores on the General Practice Assessment Survey (GPAS) and three evidence based measures of technical quality found in case records (monitoring for and control of hypertension, and vaccination against influenza) across 18 general practices in one PCT . They found that patients' measures of the care they received from their GP measured by the GPAS were unrelated to recognised standards of clinical practice recorded in the case notes. They did however, find a strong correlation between patients' own measure of technical care with their assessment of interpersonal skills, trust and communication. Despite this finding they concluded that patient surveys alone were insufficient to assess quality of care. That patient views of technical quality differed from existing clinical standards is understandable. Had the authors taken patients' measurements of technical care as the benchmark, they would in all probability have found a correlation between measures of technical care and patient-centred care.

If standards are set by the evidence base that is largely developed by clinicians rather than patients there will always be incongruence between the two. Although patients may not have the same knowledge about technical aspects of their care, the consultation is a two-way interaction between practitioner and patient, and as such the perspectives should have equal stature. This suggests that standards of care need to incorporate patient views, not only in the domain of interpersonal skills, but also in technical aspects of care.

So, to meaningfully involve patients in quality assessment there needs to be a redefinition of what is considered the benchmark for quality and what methodology should be employed in the process. For example, questionnaires can be too focussed on one area of care and are not flexible enough to capture a broad range of experiences. Campbell and colleagues (2007) reported that patients with mild to moderate mental health problems

advocated the use of questionnaires together with more interactive methods such as interviews and focus groups to reflect the diversity of patient experiences.

### ***The impact of patient surveys***

Feeding back results of patient surveys has in fact been found to have a limited impact on quality improvement in isolation (Cheraghi-Sohi & Bower 2008; Vingerhoets et al. 2001). This may be because GPs do not know how to translate the results of patient opinion into a change in quality improvement (Vingerhoets et al. 2001). They may also find it difficult to interpret the results and/or lack the motivation to use patient surveys to change their performance (Wensing et al. 2003). When used in conjunction with training however, patient surveys have been shown to have a positive effect on quality. Greco and colleagues (2001) found that systematic patient feedback at regular intervals throughout GP training resulted in sustained levels of improved interpersonal skills.

The above studies suggest that patient views can have an impact on quality improvement when they are translated into something tangible that practitioners consider both useful and easy to implement. For clinical governance this has so far been achieved using training initiatives and shared learning (Campbell et al. 2001). The problem is that the impact of training initiatives is often not sustained and has little effect on health outcomes for both young people and adults. A new form of quality improvement may therefore be required that has the capacity to incorporate patient views as a measure of quality assessment.

### **Patient involvement in questionnaire development and data collection**

Patient involvement in primary care mental health research is in its infancy but this section will review what few studies there are that have involved patients in the development of questionnaires. Again there is a lack of any separate reporting of the involvement of young people with mental health problems.

A search of the INVOLVE database identified two projects that involved consumers in mental health primary care research. Service users were involved in prioritising questions and designing questionnaires and topic guides to evaluate mental health service provision in primary care (INVOLVE 2007a). A second project involved service users with experience of severe mental illness in conducting interviews to evaluate the primary care they had received using the Verona satisfaction scale (INVOLVE 2007b). The authors noted that involvement of users as interviewers enabled access to service users that may not have agreed to take part if recruited by traditional methods such as GP request. Users of mental health services have also been consulted on completed primary care mental health projects found on the National Research Register (Department of Health 2004b).



I found only one published study that had incorporated patient views into the development of a questionnaire for primary care mental health: Mavaddat and colleagues' Patient Experience Questionnaire (Mavaddat et al. 2009). The questionnaire was based on data from six focus groups held with patients that had serious mental health problems and three focus groups consisting of patients with common mental health problems. Patients felt that the main practice-level concerns were access, continuity of care, treatment choice, waiting-room atmosphere, the attitude of receptionists, GP listening skills, GP perceived attitude towards mental health problems and shared-decision making. A majority of the focus group participants were aged 30-49 so although this is an important tool for the assessment of patient views regarding primary care mental health, it is not especially helpful in determining the views of young people.

### ***User-developed questionnaires and peer interviewers***

Patient involvement in mental health research in relation to secondary care services is more developed than in primary care. The user-focussed monitoring (UFM) project was developed by Rose (2001) at the Sainsbury's Centre for Mental Health. It involved 61 mental health service users in the research design, the data collection and analysis. The main researcher was also a service user. They interviewed over 500 service users about information, the care delivery process, clinical issues, mental health crises, user involvement, advocacy, user satisfaction with care, and the care programme approach. The model involved service users meeting three or four times and developing a questionnaire with a set of core questions which Rose argues had a different focus from those put forward by clinicians. For example when assessing experiences of taking medication, UFM groups designed questions about choice, dignity and respect, whereas Rose suggests that clinicians may be more concerned with assessing 'compliance'. It is also argued that peer interviewers elicit a more valid response from fellow service users than a researcher that has not disclosed similar experiences as is often the case in traditional research methods.

Mental health service users from the Maudsley hospital designed a 20 item questionnaire to survey the views of people who had received bilateral ECT (Philpot et al. 2004). Care satisfaction (e.g. 'do you think you made a fully informed decision to have ECT?') and adverse effects (symptoms and side effects) were assessed. Users who were experiencing ECT for the first time were less satisfied and scored higher on the adverse effects scale compared to those who had had ECT previously. The authors found that patients were more critical of their treatment compared to similar clinical studies that had not involved users in the questionnaire design.

A group of service users with a diagnosis of schizophrenia developed a satisfaction questionnaire about cognitive remediation therapy (Rose et al. 2008). The researcher, who facilitated the user group, as well as the peer interviewers, were also service users. The authors found that although service users reported high levels of satisfaction with CRT, users who were unable to conduct the tasks (as specified in the therapy), were made more aware of their disability and had lower self-esteem. As reported by the studies above, Rose and colleagues argue that involving service users in the research design, for example in questionnaire design or in choices such as the location of the research interview so that they were not necessarily being interviewed by a doctor on a ward as in other clinical studies, may have led to users to being more open about their views.

These three studies show that involving users in the design of questionnaires and data collection to assess treatments identified different aspects about the treatments than had been previously reported. This is an important contribution to the evidence base, however, the involvement of young service users was not separately reported. ECT is not recommended for people aged under 21 and therefore I would not expect young service users to have been involved in the research by Philpot and colleagues. However, young people are users of primary care, secondary care and CRT treatment but in the development of the Patient Experience Questionnaire, user-focussed monitoring and the CRT study, the views of young service users were unfortunately not separately reported. The service users involved in these studies had been using services for some time and by this very nature were usually aged over 25.

### ***Changing an existing questionnaire***

Involving users in research has become more accepted and is often an important component of service development. The following two studies illustrate how service users have been involved in adapting questionnaires used to evaluate services.

In a recent study in Italy, patients with schizophrenia were involved in the development of a questionnaire to assess the social consequences of their mental health problems (Magliano et al. 2009). Thirty-five users and 40 professionals attended 90-minute workshops to develop effective interventions, assess users' beliefs about their medication and develop information for users and carers living with the condition. The workshops resulted in significant changes being made to the preliminary questionnaire that had been developed by the research team. These included reducing the number of items, re-wording questions and changing their content. Users involved in the testing of the questionnaire rated a majority of the items as important.

A UK home treatment team involved service users in the development of a questionnaire to assess whether it was meeting the needs of its users employing a two-round Delphi technique to generate questions from 13 service users (Hopkins & Niemiec, 2006). Semi-structured interviews found that the following seven key aspects of care were considered important: access, availability, consistency (e.g. adequately briefed staff), quality (e.g. being listened to), choice and negotiation, communication and changes when service use ends (e.g. having an informed plan about leaving the service). As in the study by Magliano and colleagues (2009), service users suggested that changes should be made to the wording, layout and language used in the questionnaire.

### ***User involvement in literature reviews***

A review of service user views about ECT was conducted by three researchers, two of which had experience of ECT (Rose et al. 2004). Three sources of data were collated including attitude studies conducted by clinicians, reports written by or with contributions from service users and first hand accounts of service users views about ECT. The attitude studies conducted by clinicians reported that 70-90% of service users felt that ECT was helpful. However, the consumer-led research reports reported about half this figure. They also found that analysing the first hand accounts using qualitative methods provided a number of different interpretations. Compared to the reports written by clinicians, they argued that service user views of ECT were better understood as a complex set of 'trade offs' between the perceived costs and benefits of treatment. One of the main side effects cited in the first-hand accounts was persistent memory loss. They also found that a number of themes in the first-hand accounts such as lying about improvement to prevent further treatment and the importance of support and validation from others but that these were absent from any of the clinical attitude studies.

### ***User involvement in qualitative research***

Schneider and colleagues (2004) conducted a participatory research project with people that had schizophrenia. The project was developed in consultation with a support group for people with schizophrenia. The group decided upon the topic 'experiences with medical professionals'. As in the model of user-focussed monitoring, peer interviewing was used (the group conducted interviews amongst themselves) using a series of questions developed by the group itself. Data analysis was initially done by the members of the group who identified a series of important codes but this process proved difficult for many of the groups and so was completed by a research assistant and presented to the members for validation. The results showed that communicating with health professionals impacted upon coming to terms with a diagnosis, understanding their medication and other treatments, receiving information and support. When users felt that health professionals

were not communicating well with them they were more negative about their experiences. Conversely, positive experiences with health professionals were associated with good communication. Although there was a review of the literature on communication between health professionals and people with schizophrenia in the introduction, a major limitation was the lack of comparison of the findings with existing literature about the topic. The results were disseminated through a number of presentations to several hundred health professionals.

### **Conclusions**

The impact of user involvement on mental health research has been significant in terms of raising new research questions, effecting the outcomes that are measured (Trivedi & Wykes 2002) and the data that is generated (Allam et al. 2004) . As a result of involving service users in the development of questionnaires aspects of care that are important to service users are now included in assessment of treatments and services. However the studies reviewed above have not generally focussed on young people or on the role of primary care in mental health.

### **Patient involvement in the development of quality standards and indicators**

Improving the quality of a health service requires more than a list of what patients want or dislike. It can be difficult to translate patient survey results into something that practitioners can do or improve upon without guidance as to how to implement changes and this is where patient-developed quality indicators clearly have a role. The following studies have involved service users in the development of quality indicators.

Chew-Graham and colleagues (2002) developed suggestions for improving services and recommendations for PCTs from focus groups with Asian women aged 17-50 years old.

The service improvements included:

- An acknowledgement and recognition of the way in which mental distress manifests itself for this group;
- Understanding how Asian women may communicate their distress and that the response should be immediate;
- Providing and gathering good quality information about relevant issues such as education, employment and domestic violence;
- Providing access to interpreter and/or first language services; promoting confidentiality of services for women;
- Working collaboratively with other agencies providing support for Asian women.

Recommendations for PCTs included:

- Disseminating information about the needs of South Asian women to practices and existing resources that are available;
- To be aware and proactive regarding the development of services to meet the needs of this group;
- Involving Asian women and the services that currently support them in developing new services;
- Providing training and supervision for all staff about these issues.

Although these recommendations form an important and culturally valid set of suggestions it was not reported whether the Asian women were involved in developing the recommendations other than being focus group participants which is an important distinction.

A range of stakeholders including patients were involved, primarily through focus groups, in the development of the quality indicators for primary care mental health reviewed earlier (Shield et al. 2003). What is of particular interest is the finding that rankings between stakeholder groups differed significantly. In a follow up study, Campbell and colleagues (2004) analysed the differences between stakeholder rankings using quantitative assessment of the data and qualitative interviews with a purposive sample of stakeholders. Both patients and service providers felt that the level of self-perceived control they had on the mental health care they received and provided respectively, had an impact upon what was rated as important. However, this was conceptualised very differently between service providers and patients. Patients and carers felt they were unequal partners in negotiating their care whereas service providers identified a distinction between what was policy and what was realistically available in practice. Yet again therefore, definitions of quality differ according to which group is asked about what is important.

Differences between patients and practitioners have also been reported during the development of the QoF mental health indicators. Two patient groups, SANE and Depression Alliance, were invited to provide comments on the indicators during the development phase (Lester & Kendrick 2007). Depression Alliance suggested that people with a range of physical diseases should be screened for depression. SANE called for patients to be better informed and more involved in their treatment decisions (e.g. being asked about their treatment preferences, and exploring their opinions regarding referral). However these recommendations were rejected by the mental health expert group on the basis that there was no evidence that screening would improve health outcomes and that it would be difficult to measure whether or not a GP had involved patients in treatment decisions. Although the composition of the group was not explicitly stated, the mental health expert group did not appear to include patients. There were comments on the report

from a member of the patient participation group from the RCGP but it was not clear whether these comments had any impact on the overall report, or indeed on the quality indicators themselves. On balance there seemed to be very little meaningful patient involvement in the development of the QoF mental health indicators.

Barlow and colleagues (2007) involved 13 adults with personality disorder in the development of practice guidelines. Salient themes about interactions with staff were identified from the group discussions by researchers and confirmed by the participants. These were ranked for importance by the participants and then used to develop guidelines incorporating the mental health trust's requirements by the personality disorder working party. However, the authors did not report whether service users were involved in this final stage. Although this is an important example of user involvement in guideline development, the service users seemed to be mainly involved in the early stages and not in the final end product.

### ***Conclusions***

Patients have been involved in the development of quality indicators using a number of methods including focus groups, consultation of patient groups, and consensus methods. The studies reviewed above also illustrate that there are differences between what patients and practitioners consider to be high quality. None of the studies involved young people with mental health problems. In addition, I have found no published quality indicators regarding youth mental health problems for use in primary care. If we are to develop primary care services that meet the needs of young people with mental health problems, quality of care should be defined from their perspective as well as that of service providers.

### **Youth participation in healthcare research**

Prior to the late 1980's there were not many examples of successful youth participation in healthcare. One of the first was initiated by The World Health Organisation (WHO) and International Association for Adolescent Health (IAAH). In what was considered an 'unprecedented' approach, young people were involved in the Health of Youth part of the World Health Assembly in 1988, informing delegates of the issues facing the world's youth through music and theatre (Bennett & Tonkin 2003). Since then health providers have come to recognise the importance of involving young people in healthcare. Indeed, encouraging participation and the empowerment of young people is one of the main underlying principles of youth work (Young 1999). The WHO continues to promote the involvement of young people through initiatives such as the World Health Youth Environment and Health Communication network (WHO 2009).

Youth participation in healthcare traditionally takes the form of consultations and studies about young people's views on the healthcare they have received (Bennett & Tonkin 2003) and young people are both known to want health services to improve and feel that they have the capacity to be involved in processes to achieve that end (Macdonald et al. 2007) . There have been examples of youth participation in medical education (Fallon et al. 2008; Greenhalgh 2006) and in health promotion (Robottom & Colquhoun 1992) and young people have had positive experiences of being involved in health service development when they receive repeated feedback over time, are consulted on topics chosen, and an adult has a formal role (Lightfoot and Sloper 2003) .

The following studies describe examples of youth involvement in health services research. Percy-Smith (2007) trained 11 peer leaders aged 14-19 years old in research methods. They were then asked to explore their peers' interpretations of health concerns using their preferred research method. They conducted the research in schools, colleges and with peers on the street in their neighbourhoods. The research methods chosen by the young people were not clearly reported but the results were presented as pictorial illustrations of experiences of stress, pressure from exams, lack of trust in doctors, body images, and recognizing the need for support. They found that stress and psychological well-being were the most important health concerns for young people. The results (illustrations) were presented at a learning event attended by 62 young people and 36 professionals.

The authors stated that they used grounded theory to analyse results but it was not clear what these results were as they presented only anecdotal quotes from participants to illustrate the pictorial themes. The authors argued that current policy does not reflect these interpretations but this was largely unsubstantiated. It can be argued that existing policies do in fact support the insights delivered by the young people on health concerns. For example, as discussed earlier, all guidance for youth health services states that practitioners should explain confidentiality to young people during the consultation which could go some way towards addressing young people's lack of trust in doctors found by Percy-Smith and colleagues.

It may have been more useful for Percy-Smith to explain how the results added to current NSF and DH standards, thereby further developing the evidence base for youth participation in healthcare research. Percy-Smith stated that the objective of this 'peer research' was to promote a dialogue between young people and professionals and proposed that a new shared learning may develop between young people and professionals by which some form of social action would take place to address the concerns that had been raised by the young people. However, they found that no change had occurred one year later, not because of the research process, but because of the professionals' pre-occupation with the need to implement other current policies.

Jackson (2003) used drama to present young people's concerns about primary care health services to professionals. Fifteen 12-16 year olds presented the main theme entitled 'improving relationships between young people and professionals'. Themes included:

- lack of information and misunderstanding about confidentiality,
- parental consent and young people's rights;
- perceived lack of respect;
- feeling unwelcome at the practice
- A perception that services were directed towards older people.

Drama proved a successful method of engaging young people and conveying messages to professionals but it was not clear what action was taken as a result of the process as the authors neither reported professionals' views about the event or whether any changes were found as a result of the intervention.

Moules (2009) involved nine young people aged 12-16 years with experience of in-patient hospital care as co-researchers to investigate young people's definitions of quality of care. Each co-researcher was initially interviewed about their own experiences and asked to rate the clinical and nursing interventions they had disclosed. The nine young people were involved in the data analysis of the interviews alongside the researcher using a modified version of framework analysis method. This resulted in the following five characteristics which were associated with excellent care:

- Technical expertise
- Explanations
- Choice
- Friendly staff
- Respect

The young people decided to investigate whether these aspects were similar to other young peoples' perspectives of quality care. They developed a vignette based on the five quality characteristics developed by the co-researchers and asked 129 pupils from a local school aged 9-14 to identify the best and worst aspects of care and to rank them by order of importance. The findings were related to the five original characteristics of quality identified by the co-researchers. No other themes were reported which indicated that the research team may have been biased towards their own areas of quality and did not consider other interpretations of excellent care that may have been suggested by their participants. Although these findings outline the aspects of care that young people consider to be important, they remain implicit broad concepts that are open to many different interpretations. In order to be implemented by practitioners they would need to be



translated into explicit statements of practice so that practitioners could attempt to incorporate them by modifying their attitude or behaviour.

Laenen (2009) used focus groups and nominal group technique to elicit the views of young people aged 12-21 years with emotional and behavioural problems about their preferences regarding drug prevention strategies. The young people devised the research question, developed and completed a survey and decided upon how the results could be best implemented in practice. Although young people were involved in the development of the guidelines, the guidelines themselves were not reported. Instead, Laenen focussed on the process of involving young people with emotional and behavioural problems in research. Whilst welcoming the opportunity to have an influence on drug policy, many of the young people were unused to being consulted and were initially distrustful of the researcher, despite assurances that the focus groups and nominal groups were confidential. This was illustrated by the disclosure of socially acceptable answers in the beginning of the research leading eventually to more realistic responses as involvement developed over time.

### ***Limitations of youth participatory research***

Participatory research is an effective method to engage young service users and professionals in the research process but there are a number of limitations shared by the studies reviewed above. Firstly the reporting of participatory research often focuses on the processes involved in participation rather than the outcomes which are more difficult to identify (Oliver et al. 2004). When outcomes are described they are usually either couched in terms of social action or they are difficult to define in practice. The problem with social action as an outcome is that it requires further funding to evaluate the impact of the process. There is also a paucity of evaluations monitoring the impact of participatory research and often, when impact is recorded over time, there is either no change or short-term changes are not sustained (Fudge et al. 2008).

The results of participatory research often come in the form of large-scale recommendations to change systems (e.g. Percy-Smith's recommendation to change the education system so that learning is not about exams but improving emotional resilience). Such recommendations can be completely unrealistic for practitioners to implement, or unrelated to everyday practice, or so loosely defined as to be difficult to understand, which may account for why no changes are often found to have taken place.

Tangible results such as a quality indicator which explicitly states the way that practice should be improved could enable system changes to be put into place allowing professionals to initiate the changes suggested by the authors of PR projects. This may enable more realistic and collaborative efforts to change knowledge, attitudes and

behaviour. Hence research that both involves patients and provides guidance for practitioners may be more successful in improving the quality of care.

### **Rationale for the study**

Young people are a vulnerable group. The Department of Health has tasked primary care with meeting the needs of young people with mental health problems (NICE 2005). However, young people with mental health problems often do not access help from their GP (Biddle et al. 2004) and they report the GP and primary care experience as problematic when asked about seeking help for mental health problems (Biddle, 2006; Buston, 2002; Leon, 1999). Young people without mental health problems also consider GPs to be less desirable sources of help compared to counsellors, family and friends.

Survey studies have mostly used questions that have been pre-determined by researchers rather than service users to investigate young people's views which has the effect of limiting the findings to those aspects of care that the researchers deem to be important. Previous qualitative research has not included (or analysed the data with regard to) participants from a wide range of vulnerable groups such as those from ethnic minorities and the homeless.

Involving patients in research and service development is advocated by government policy but there is currently little knowledge of the impact of patient involvement in service provision. In mental health this takes place largely through surveys but the effect of these on service development also remains to be evaluated.

Previous work defining quality indicators for primary care mental health has not focussed on young people, and has not involved young consumers as co-researchers (Shield et al. 2003). This study will go beyond describing the views of young people, both those with and without mental health problems, by translating the concerns of young people into a set of quality indicators for primary care practitioners. This will deliver tangible results that can be evaluated.

The patient-developed quality indicators will also be presented to primary care practitioners to assess their usefulness and identify ways that they can be incorporated into practice. It is hoped that exploring these issues through collaborative research will go some way towards closing the gap between young people's views and behaviour, and the expectations placed on primary care practitioners regarding the mental health needs of young people.

The following chapter will present how this is to be achieved using participatory methodology with young people as co-researchers and as members of an expert consensus panel.

## **CHAPTER THREE: PARTICIPATORY RESEARCH METHODOLOGY AND METHODS**

This chapter presents both the theoretical perspectives guiding the research and the methods used to achieve the study aims. These will be divided into the following five areas:

- Theoretical perspectives and participatory research methodology: I review the ontological and epistemological questions that have shaped this thesis. I will explain how the principles of critical theory underpin the participatory research methodology adopted throughout this study.
- Overall study aims, design and rationale.
- The development of the quality indicators with young service users.
- Primary care perspectives on the quality indicators: I will describe how the quality indicators were presented to primary care practitioners by young services users; focus groups and interviews to assess their views on the usefulness and applicability; and how the data were analysed.
- Development of thematic networks to understand young people's views on help seeking: I will present a separate thematic analysis that was conducted to explore young people's views about seeking help for mental health problems and the role of primary care.

### **Theoretical perspectives of the research**

Because the aim of any research endeavour is to produce new knowledge, we must concern ourselves with what knowledge we consider to be valid evidence, or in other words, what we consider to be real and true. In approaching this question I will present three broad paradigms operating within health services research: prediction, the interpretive-constructive paradigm and critical theory. I acknowledge that there are a number of different interpretations operating within each paradigm, however, to present each of these is outside the scope of this thesis. As such, this is not an exhaustive list of theoretical orientations adopted in health services research. The aim of this section is to present a broad overview of the ontological and epistemological questions that have

shaped health services research and describe the theoretical assumptions underpinning this thesis.

### ***Prediction paradigm***

Positivism is the philosophical basis of the natural sciences. The underlying assumption is that reality is a stable entity. This means that reality exists whichever way we choose to investigate it. It also implies that there is one true reality and that science is based on these "certain" facts. This enables a researcher to be separate from reality and, because we can be objective, we can also measure this reality. From this position, in other words, the researcher is both neutral and objective. This has been well summarised by Crotty (1998):

*'Whereas people ascribe subjective meanings to objects in their world, science really ascribes no meanings at all. Instead it discovers meaning, for it is able to grasp objective meaning, that is, meaning already inherent in the objects it considers...from the positivist viewpoint objects in the world have meaning prior to and independently of, any consciousness of them'* (Crotty 1998, pg 27)

Historically, science was considered to be the search for universal laws that could be empirically measured and replicated. From this position, scientific claims are based on quantifiable propositions that can be expressed as mathematical formulae describing functional relationships (Guba & Lincoln 2004). As such, the aim of a positivist investigation is to explain and predict phenomena. Due to the assumption of objectivity inherent in the positivist approach, research is also considered to be value free. This separates science from society in that it assumes that science is not bound in emotional, subjective and political standpoints (Green & Thorogood 2004). However, philosophers of the social sciences began to question the notion of a stable, observable reality and acknowledge a more changeable one. This led to the move away from the natural sciences towards the development of a 'social' science.

### ***Critiques of positivism***

One of the most influential critiques of positivism came from Thomas Kuhn's 'The Structure of Scientific Revolutions' (Kuhn, 1962). Kuhn argued that science is far from being objective, infallible, and unchallengeable. Rather, Kuhn posited that human values, and therefore human errors, are embedded within the practice of science (Crotty 1998). This led the way for further criticisms aimed at positivist inquiry based on the acknowledgment that human perceptions are unavoidably flawed. These claims meant that reality could only be understood imperfectly. If one takes Kuhn's position, explaining phenomena with any certainty becomes problematic because it is accepted that knowledge is inextricably linked

to historical, cultural and social structures. This led to the consideration that knowledge is relative rather than absolute (Patton 2002). As a result, science was now concerned with trying to disprove that something existed rather than attempting to prove that it existed (through the null hypothesis). Thus, post positivism, as it was now referred to, moved from a practice of theory verification to one of theory falsification. This remains the benchmark of quantitative research methods. It is also the basis of some forms of qualitative research (see critical realism below).

Another critic of positivism was Karl Popper. In his theory of falsification Popper argued that observation and experience do not precede expectation but that expectation precedes observation. In other words, we learn about the world when our expectations prove false (Gorton 2006). However, as previously described, theory falsification proved problematic when applied to the social sciences (Gorton 2006). This is because the complexity of social phenomena, together with the lack of explanatory universal laws, makes precise predictions difficult (Sceski 2007). When it comes to dealing with social sciences, Popper shifts his thesis towards 'situational analysis' in which he proposes that individuals act rationally according to their social situations (Gorton 2006). Although labelled as a positivist, Popper's acknowledgement of the role played by context paved the way for a consideration of the way social structures impacted upon knowledge production, and thus what is considered to be reality.

### ***Critical realism – further critiques of positivism***

Critical realists consider there to be an objective world representing reality, but acknowledge that it is situated within social, cultural and historical structures. That means that although there is a reality that exists independently, the way that it is perceived is a product of social interaction. So, the existence of an objective world means that there are stable relationships to be found within it and realists are concerned with explaining these:

*'We think that social phenomena exist not only in the mind but also in the objective world – and that some lawful and reasonably stable relationships are to be found among them. The lawfulness comes from the regularities and the sequences that link together phenomena. From these patterns we can derive constructs that underlie individual and social life.'* (Miles & Huberman 1994, pg. 10)

For critical realists material reality constrains action but does not determine it. At the same time, social structures are only relatively enduring as they are dependent on time and space. As a result they are not universal (Rogers & Pilgrim 2005). This position supports the socially constructed nature of society (e.g. political, economic and cultural structures)

and not the theory that reality itself is socially constructed (Bhaskar 1989), as described below.

### ***Interpretive-constructionist paradigm***

Predicting and explaining phenomena has been criticised for providing limited explanations of behaviour. Within the interpretive approach there is no one single objective reality that can be isolated, investigated and explained. Rather, the assumption is that we make sense of our world by experiencing phenomena, although this experience requires interpretation in order to be understood (Patton 2002). To undertake interpretive inquiry is to pay attention to the lived world of participants and to understand the meanings that phenomena hold for them in everyday life (Angen 2000). This process of interpretation takes place within a specific context and is based on interactions between researchers and participants. Therefore it is important to be explicit about one's assumptions as these will impact upon how meaning is understood through the experiences of others. This position celebrates the subjectivity of the researcher and is concerned with its impact on the research. Rather than moving oneself away from the lived world in an attempt to obtain objectivity, interpretive inquiry requires a conscious embracing of subjectivity in an attempt to ground the research in the lived worlds of the participants. This enables researchers to investigate phenomena from a different standpoint, where one is not necessarily better or higher than another's (Hense-Biber & Leavy 2004).

### ***Social constructionism***

Social constructionism takes the importance of subjectivity and context further by asserting that reality only exists (object) because it is given meaning by another person (subject). The main tenet of social constructionism is the concept that language is used by social beings to co-construct reality through interaction (Berger & Luckman 1966). Accordingly there is not one single stable reality, but many different interpretations of reality. From this perspective there are no true or valid interpretations only 'useful interpretations' (Crotty 1998). As a result, reality can exist in multiple forms according to that which is socially constructed (Guba and Lincoln 2004). Research conducted from an interpretivist-constructionist perspective would expect that different groups of people have different experiences but that each is as valid as the other and that these interpretations are constructed between the researcher and participant (Patton 2002).

Critiques of social constructionism argue that it is a futile exercise to claim that multiple realities exist as this refutes anything certain being said about a phenomenon. In other words, if there are many different versions of the truth this negates any reason for conducting research since all we are doing is defending our favoured positions. A further

criticism faced by such relativism is the concern that if all knowledge is valid you cannot critique it. Alternative paradigms have emerged that recognise the role of social construction upon interpretations of reality. For example, although critical realism considers reality as an objective entity it is posited that we make sense of it through social interaction (see above).

### ***Critical theory – historical realism***

The paradigms discussed above have been central to the debate about the role played by social interaction in shaping reality and what constitutes knowledge. However, some posit that these approaches have paid insufficient attention to the role of history and the political structures that are produced by different social positions of individuals (Mertens 2003). Critical theorists develop this argument further by advocating that socially created knowledge entirely reflects the historical, economic, cultural and political structures within which it is produced (Kemmis & Wilson 1998). There are many forms of critical theory and to describe it as a uniform theory would be rather simplistic. For the purposes of this thesis the main foundational aspects of critical theory that are important here are presented below.

As with previous theoretical positions, critical theory emerged through a critique of positivism (Outhwaite 1987). In *Knowledge and Human Interests* Habermas claims that positivism had obscured the way in which science and the pursuit of knowledge shapes nature and society. He argued for the development of a social theory of knowledge. Through what Habermas termed as ‘knowledge-guiding interests’, he argued that humans had agency through cognitive functioning. The notion that humans are active beings is based on individuals having the ability to be reflective. It is considered to be part of the human condition to ask questions of oneself such as ‘what kind of person would I like to be?’ and to evaluate one’s own desires and beliefs against one’s current feelings and expectations. Being active allows humans to change at least part of their social world, and this shapes their identity (Fay 1987). In other words the process of action and reflection is manifested as an examination of one’s position or standpoint. Kemmis and Wilkinson (1998) consider reflexive practice to be an interplay between the objective (how people act upon something) and the subjective (how something is internally understood):

*‘Changing the objective conditions changes the way in which a situation is interpretively understood, which in turn changes how people act on the ‘external, ‘objective’ world, which means that what they do is understood and interpreted differently, and that others also act differently, and so on, in a dynamic process of reflection and self-reflection which gives it human action in history its dynamic fluid and reflexive character’* (Kemmis & Wilson 1998)



The historical roots of critical theory can be traced back to Marxist propositions that humans who possess (economic) power are able to shape the perceptions and viewpoints of those who do not. This leads to the imposition of a system of beliefs which is not seen for what it is (exerting power over others), but is taken to represent reality (Crotty 1998). The notion that individuals can improve their social position through improved knowledge of their situation was the basis of Paulo Freire's (1970) seminal text *Pedagogy of the Oppressed* in which he argued that human beings are able to realise their subordinate position in society through increasing their 'consciousness'. For Freire this process was inextricably related to action. In fact, Freire considers reflection and action to be the process by which human beings create their very existence. This becomes *critical thinking* through its use as a tool to enable people to realise their position in society. It is also an inherently social process, as the act of critical thinking takes place through dialogue with others (Crotty 1998).

Critical theorists do not subscribe to the idea that there is a dichotomy between objectivity and subjectivity, but consider there to be a unity between the two which is realised in the act of knowing. In this way consciousness is not a reflection of reality itself, but is a reflection *upon* material reality (Crotty 1998). Critical theorists subscribe to the following assumptions (adapted from Kincheloe & McLaren, 2005):

- All thought is fundamentally mediated by power relations that are social in nature and historically constituted.
- Facts can never be isolated from the domain of values.
- Certain groups are privileged over others and this is reproduced when subordinates accept their social status as normal.
- Mainstream research practices are generally, although unwittingly, implicated in the reproduction of social structures.

There are similarities and differences between critical theory and critical realism. Both differ from naïve realism in that they recognise that thought is a reflection on reality which is socially constructed. Critical theorists are particularly concerned with the role of power differentials and disparities between different groups in society, and their impact on consciousness. Critical realists assume stable relationships within reality and so are concerned with explaining causal pathways. Critical theorists on the other hand believe that these relationships are far from stable but in fact are open and require examination so that reality can be changed – the very act of thinking critically is to develop a new reality (Kemmis & Wilson 1998). Research undertaken with a critical theoretical stance is therefore a transformative endeavour which aims to expose the underlying historical, political and social structures upon which knowledge is based. Hence it is seen to be a form of social and cultural criticism.

Taking a critical approach to Health Services Research (HSR), I argue that it is largely concerned with questions about efficacy of interventions and effectiveness of treatments. These research questions have been well served by the existing dominant methodologies of post-positivist (usually quantitative) research. However, with the idea that an individual could exercise democratic power at any level of society including healthcare, different research questions have had to be asked of health services research. Patient involvement in research has also led to new ways of generating data which has been achieved using the model of participatory research.

### **Participatory research: from theory to method**

Participatory research has been traditionally used in developing countries where whole communities were encouraged to affect social change through empowerment and consciousness raising. This was achieved by inviting a researcher to come into the community to encourage the members of the community to raise their level of knowledge about their social situation. The effect of this was that the individuals involved in the research process were participants rather than subjects. The 'action' came from participants' examination of the impact of existing social structures on the community and on individuals (Ernest 1996). This empowered individuals to challenge their position in society and existing power differences that may have contributed to disparities between groups.

In health services research, the terms participatory action research (PAR) and participatory research (PR) are often used interchangeably (Cornwall & Jewkes 1995). Throughout this thesis the methodology will be referred to as participatory research (PR), although I acknowledge that there are differences between the two models. In an action research (AR), a researcher works with an existing community but is not necessarily from that community. In a participatory research project, there is a blurring of the boundaries between who is the researcher and who are the participants. PR shares the concerns of action research by critically examining the status of individuals. Similarly, PR is not incompatible with other epistemological approaches such as an interpretive-constructivist position which recognises that participant's stories are co-constructed through interaction between the participant and researcher.

PR differs from other approaches in that it is explicit about the relationship between knowledge and power (Thesen & Kuzel 1999). Therefore, research is conducted within the context of democratic equality. A PR project attempts to reduce the power differential between researcher and participants through reflexivity, disclosure, and involving participants as co-researchers. This illustrates how critical theory is compatible with the

methodology of participatory research. Critical theory assumes that knowledge is value laden and PR demands that structures of power are removed in an attempt to scrutinise them, and by doing so realise new knowledge. Hence traditional power differentials are removed by elevating patients from the role of research subject to that of co-researcher. This is not easy to do (see, for example, Mason and Boutilier 1996), and conducting participatory research requires a critical approach to be taken towards the established relationships that exist between researchers and participants. Depending on the level of involvement, the patient as co-researcher can be involved in all stages of the research cycle. As has already been described, treating research as a co-operative exercise between researcher and participants shifts the balance of power so that it becomes more equal. Therefore, I argue that PR methods are the most appropriate for conducting research from a critical epistemological position.

The importance of equity between researchers and participants is well illustrated by Reason and Rowan's (1981) model of 'co-operative inquiry'. Their approach considers research as a collective endeavour between co-researchers so that conclusions encompass different ways of knowing (Reason 1994; Reason and Rowan 1981). They argue that valid research should include feeding back results to co-researchers, making changes based upon their comments and thereafter planning further research in the light of these results. The notion of consulting with participants acknowledges the effect that taking part in research may have on them (Reason & Rowan, 1981). This process requires researchers to be aware of how processes might affect their participants as well as being explicit about one's own assumptions regarding the research process. Koch and Kralik (2006) refer to this concept as 'relational ethics' whereby the perspective and vulnerability of another person is acknowledged.

Another key difference between PR and more traditional research methods is the overarching concern with producing social change (Rowan 1981). This can manifest itself as consciousness raising or behaviour change in the individuals involved in the research process (Koch & Kralik 2006). As researchers and participants occupy roles that they have not held previously, they raise novel questions and make different interpretations because new, previously unsought perspectives are brought to the research process. Beresford (2005) argues that involving service users improves the accountability of research as it is informed by their needs and experiences. He further asserts that service user involvement in research can identify health inequalities through the participation of people who are disadvantaged or excluded, such as people receiving mental health services, black and minority ethnic service users and homeless people. Therefore, research that actively involves service users from these groups may increase understanding about the reasons for health inequalities.

Young people are also a group that were traditionally excluded from the mainstream as decisions were made for them without due consideration for their perspectives. This situation has changed considerably with the advent of youth participation and involvement in the education, health and social care sectors. PR is a popular method for working with young people. Rodriguez and Brown (2009) propose three guiding principles for conducting PR with vulnerable young people. They posit that research should be:

- Situational and inquiry-based: research is based on real-life problems that are experienced by the youth researchers so that the research has meaning for them.
- Participatory: power is not considered to be oppressive but is embraced as a necessary tool to use with, and not upon, young people to build relationships and promote collaborative learning. This is referred to as the 'relational understanding of power'.
- A commitment to research and learning with the specific goal of having an impact upon changing knowledge and practices in ways that improve the lives of marginalized youth.

I will now show how the methodology described above relates to the aims of the study and the methods used to achieve those aims.

## **Study Aims**

The principles proposed by Rodriguez and Brown (2009) above are a useful way of locating the aims of this thesis:

### ***Aim 1***

The overall aim of this thesis was to involve young people in the development of quality indicators for primary care mental health. This was to address the lack of youth-generated quality indicators in primary care. Using a participatory research approach enabled young people with mental health problems to have a meaningful impact upon the way that data was generated and interpreted.

### ***Aim 2:***

The second aim was to investigate primary care professionals' views about the youth-generated quality indicators. As the project progressed, involving young people with mental health problems in the research process proved to be both feasible and empowering for myself and the co-researchers. So that we could continue the work we had done so far, I felt it was important to ask primary care practitioners about their views on the quality indicators. This was seen as an effective way of disseminating the quality indicators, with

the potential to produce a change in the knowledge and practices of primary care practitioners.

***Aim 3:***

The final aim was to explore young people's views on help seeking for mental health problems and the role of primary care. As has been shown in the literature review, young people often report negative experiences of primary care and those that experience mental health problems often do not seek help. This is a 'real-life problem' that has an impact upon the well-being of young people experiencing a mental health problem.

**Study design**

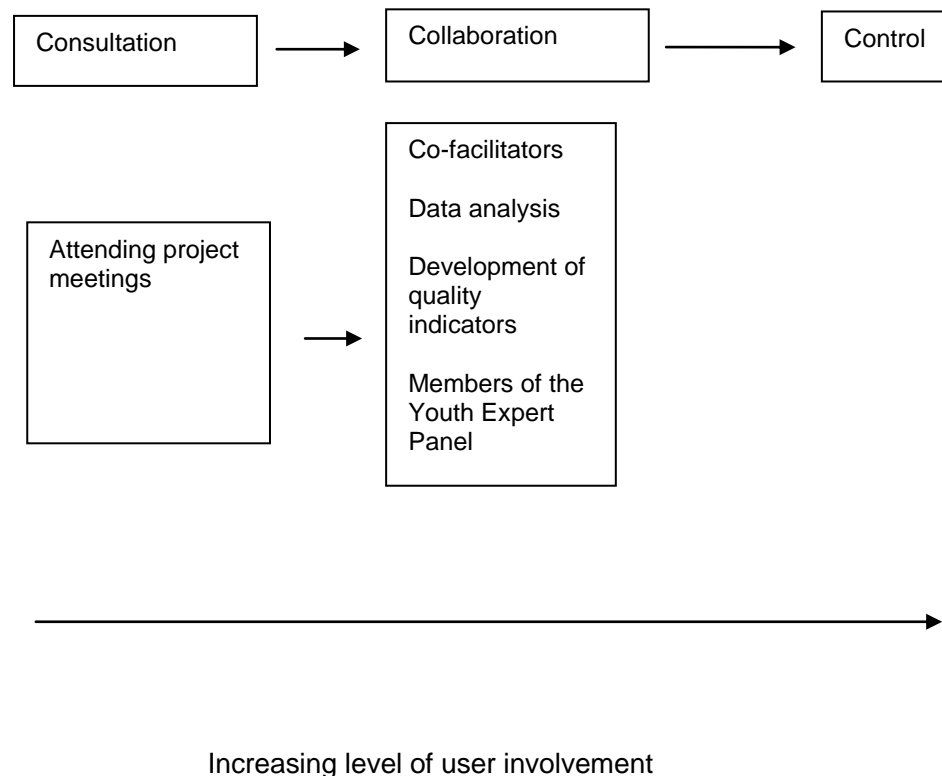
A participatory approach involving young service users as co-researchers and members of an expert panel was used, with focus groups and nominal group techniques employed respectively. The participatory model was used in the six stages during the course of the study:

- Young service users were recruited and trained to take part as co-researchers.
- Focus groups and interviews were conducted with young people (both with and without mental health problems) about their views on the appropriateness of primary care as a source of help for mental health problems. These groups were co-facilitated by young service users.
- During the third stage, young service users, GP academics and I allocated data from the focus groups and interviews to a coding framework.
- Next, the quality indicators were developed from the coding framework through a series of Participatory Research Groups (PRGs) with young service users.
- In the final stage young service users were recruited to join a Youth Expert Panel tasked with reaching agreement on which quality indicators were the most important via nominal group technique.
- Young service users also co-facilitated the focus groups (6 or more participants) and mini focus groups (3 participants) with primary care practitioners and took part in multiple coding meetings to interpret the data.

As illustrated in figure 2 the lowest level of involvement was through attending and contributing to project meetings. Becoming more active members in the research and

contributing to data collection and analysis was achieved in stage 2. Finally, in stage 3 young service users were given the power to decide which quality indicators should be included in the final list for practitioners. Ethics approval for the study was obtained from the institute of Psychiatry Ethical Committee.

**Figure 2: Spectrum of user involvement (adapted from Hanley et al 2003)**



***Rationale for study design***

Punch (2005) refers to a number of key questions that should be addressed when considering which research methods to use. In the first instance, he stresses the importance of matching the methods to the research question. In asking the question ‘What *exactly* are we trying to find out?’ the dimensions of a chosen method are clearly marked and it encourages evaluation of whether it will enable one to address the problem that has been identified. Secondly, he posits that it is important to consider what has already been written about the topic and to question how the proposed research will add to existing literature. Finally, he suggests that the researcher pay attention to which methods will produce more useful knowledge (what he terms ‘knowledge pay off’). This will orientate the researcher towards a particular methodology.

It is useful to consider these three points when reflecting upon the rationale for conducting participatory research with young service users. The overall aim of the project was to develop quality indicators for primary care professionals regarding youth mental health. A participatory research model was adopted because it was considered important to develop the quality indicators with significantly more involvement from young service users than had previously been achieved in order to incorporate their perspectives into improving primary care for this group. Correspondingly, an integral part of this thesis is to critically examine the way that existing quality indicators have been produced.

The next section will discuss how the methods chosen for this thesis were appropriate to and complemented group work with young service users.

### **The use of focus groups and nominal groups in participatory research**

Qualitative methods are often used within a participatory framework for health services research (Meyer 2000). The aim of qualitative research is to determine an individual's interpretation of a phenomenon. Therefore the patient's perspective is pivotal to studies using qualitative methods. One way to assess rigour in qualitative research is to establish the extent to which data collection and analysis is a valid explanation of the participant's account (Mays & Pope 2000). This means involving participants in the analysis process so that their response impacts upon the way themes are developed. The central tenet of PR is to incorporate participants' views and experiences into the research process by involving them as co-researchers. Although it is important to make the distinction that qualitative methods are not the same as participatory methods, they do complement one another because both attempt to maintain the 'voice' the patient throughout the research process.

Focus groups and interviews allow us to probe into the worlds of our participants and obtain rich data about the subtleties and nuances that accompany young people's decisions about whether or not to seek help for a mental health problem. Perhaps more crucially, qualitative methods also allow the development of a rapport between the researcher and a young person. At the same time, meeting others with similar experiences and sharing their perspectives can enable a rapport to be established between all the participants. Focus and nominal group guidelines stress the importance of respect for one another, as well as confidentiality among the group, all of which serves to build the young participant's trust.

Focus groups were employed in order to involve young service users in the research process. They were also able to bring their experience to the research by being focus group co-facilitators. Young service users were able to ask questions, write co-facilitator (field) notes, contribute to debriefing meetings after the focus groups, and comment on the

themes as they emerged. Through these means, the process of contributing to data generation enabled young service users to be meaningfully involved in the development of the quality indicators.

Nominal group technique (NGT) is used to reach group agreement through interaction. Although members will agree and disagree on particular aspects of the discussion, the overall aim for a focus group is to establish group norms but not necessarily agreement (Kitzinger 1994). NGT is used to determine a specific level of agreement on a particular issue. We wanted to present areas of practice that were considered to be the most important by a group of young service users so that practitioners felt the quality indicators were valid and meaningful. Therefore, nominal groups were required in addition to focus groups.

As with focus groups, nominal groups complement the participatory research design as they enable participants to interact with one another. Sharing experiences and reasons for allocating a particular ranking are important aspects of the nominal group process. These activities enabled participation by encouraging young service users to share experiences and views in a safe environment with people who had similar experiences. Being a member of the nominal group empowered young services users to make meaningful decisions about the results of the study.

### **The importance of reflexivity**

Being transparent about our assumptions and drawing on our own experiences is an important aspect of validity in qualitative research. This is commonly referred to as reflexivity, and it is drawn upon heavily in a PR project because of the importance attached to equality between researchers and participants. Murphy and colleagues (1998) report that alternative criteria for assessing studies using critical theory have been proposed, including an assessment of the extent to which the research process is democratic. As we are asking participants to reveal their experiences and bring them to the research process, as researchers we too must do the same. Being explicit about what we as researchers know and do not know is crucial because our position as researchers impacts upon the research cycle. As stated above, researchers are not objective but are situated within the worlds that they are researching. More radical authors claim that validity in research can only be maintained if the co-researchers engage in some systematic method of personal and interpersonal development (Reason & Rowan 1981). Disclosure of assumptions and experiences between researcher and participants can be seen as a method of addressing the power differentials in an attempt to reduce the differences. This can produce a more democratic and equal footing for both researcher and participant to proceed. Having had



counselling myself, I was also able to match the experiences of many of the co-researchers and participants. See box 4 (below).

### ***Professional background***

After obtaining my Masters in social psychology at the London School of Economics in 2000 I joined the Institute of Psychiatry in 2001 and began working on an anti-stigma project which involved secondary school pupils and the police (Pinfold et al. 2001). Since then I have worked on six different research projects as a qualitative researcher investigating patients and professionals views of mental health services and treatments. As a non-clinical researcher I observed that much of the research on health services is largely shaped by the views of health professionals. In addition my background in social psychology and in particular my interest in social constructionism (discussed earlier) led me to consider the importance of generating knowledge from different perspectives. This influenced me to take a critical approach to the issue of youth help seeking and the development of quality indicators using participatory research with young service users. I believe that being a non-clinical researcher has enabled me to incorporate my experiences as a primary care patient more than a clinical researcher would as I may be more relaxed about maintaining the professional boundary that exists between a practitioner and their patient.

### **Box 4 Disclosure of personal experiences**

During my early twenties I went through a difficult period that coincided with my parent's divorce. Through my mother's profession as a therapist, I was able to access individual and group counselling which I found extremely helpful. It did not occur to me to seek help through my GP. I did not even consider the GP surgery to be a place that would offer help to a young person in distress. In retrospect, having my mother's connections in the field of counselling was the main reason that I was able to access therapy. Because of my experiences as a young person, I have always felt that it is very important to help others that are at this vulnerable stage of development. I feel an affinity with young people because during the same period in my life I faced and dealt with many challenges. I do not claim to have had a difficult life – indeed I have had a great deal of privileges - but I have chosen to combat emotional upsets in my life using individual and group therapy.

## **Identifying, recruiting and engaging young service users for development of the quality indicators**

Thirty-four young service users were recruited as co-researchers during the four-year project. Young service users were defined as individuals aged 16 to 25 years old that had sought help for a mental health problem from either statutory or non-statutory services within the last five years. To ensure that young people who were not registered with a GP (e.g. homeless) or who may not have returned a letter sent through the GP were included, it was considered important to sample from a wide range of community services. Two GP surgeries sent letters to all registered 16-25 year olds with depression inviting them to contact the researcher for more information about taking part in the project. I also presented the project to staff at four Child and Adolescent Mental Health Services (CAMHs). Each CAMHs team agreed to place an advert and fliers in their waiting rooms inviting young people to contact me by text message, email or phone. Adverts and fliers were also placed at two local black service user groups and a student counseling service from a local university. Over the following year adverts and fliers were also placed at 6 further recruitment sites: a local adult psychiatric outpatient unit, a youth drug and alcohol service, an early psychosis intervention unit, and two hostels for homeless young people. The project advert was also placed on a local eating disorders clinic's website.

Young service users who contacted me were asked about their experiences of mental health problems to ensure that they met the inclusion criteria. I informed young service users of my own experiences of counselling. For those young service users who met the criteria and wanted to take part, I also met them on a one-to-one basis to develop a rapport which aided the process of engagement. At the beginning of the project, 12 young service users were recruited to attend a social event. The objective was to provide the opportunity for the young service users to meet each other and give them more information about what being involved in the project would entail. They took part in a series of exercises aimed at getting to know each other and learning how to work with others as part of a team. I facilitated this group alongside a youth worker with experience of working with young service users. Afterwards, the group went to a local restaurant for dinner. The young service users were invited to take part in subsequent co-facilitator training sessions which are described below.

Directions and a letter detailing the agenda for each of the meetings were sent to all young service users agreeing to take part in the project. I also sent train times to young service users who had said that that would be helpful, and they were also called to confirm their attendance the day before and on the day of each meeting. Informed consent was sought from each young service user on or before attendance of the project meeting(s). Each young service user was paid ten pounds for their time and travel expenses were

reimbursed. I also encouraged young people who contacted me to pass on the invitation to others with experience of seeking help for mental health problems (known as snowballing). Following an initial recruitment phase, young service users who met the definition criteria were invited to participate throughout the course of the project. For example, young people who had disclosed that they had sought help for a mental health problem during the pilot work and focus groups were invited to contribute to data analysis and the nominal groups.

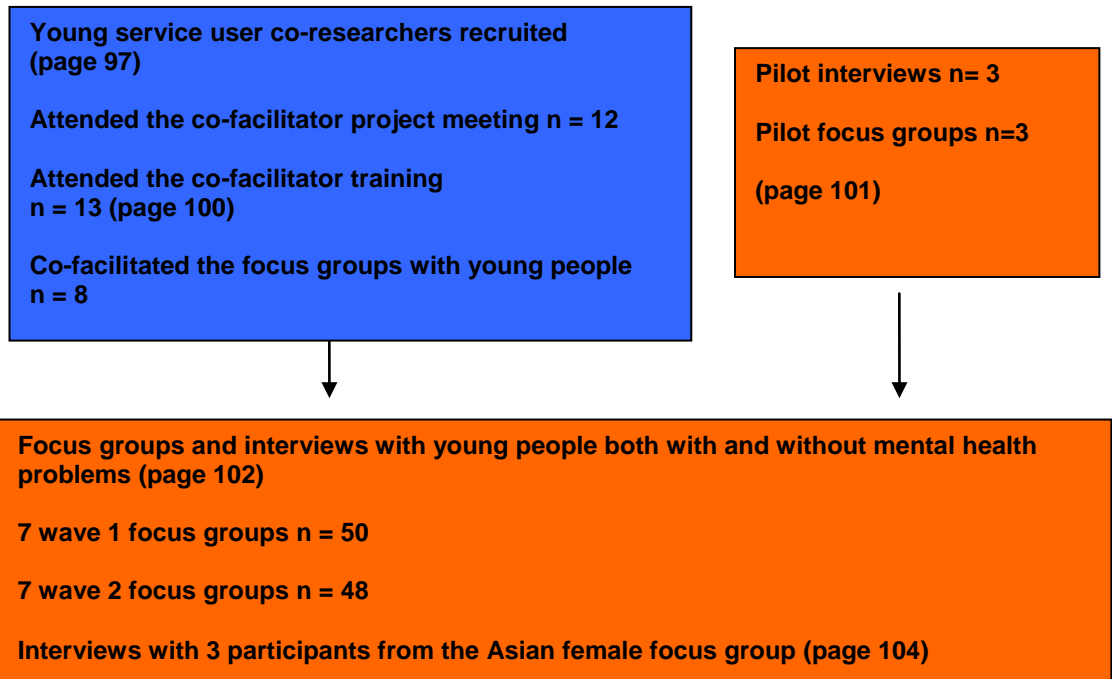
Having had similar experiences to those of the participants influenced my approach compared to that of a researcher without such experiences. As a researcher with experience of being a vulnerable young person who often disengaged with health services I was able to approach the recruitment process with greater sensitivity. For example, I was able to empathize with the participants on how they might feel about being asked to talk about their experiences and take part in the research by expressing how I might have felt in similar circumstances and by outlining my own experiences that were similar to theirs. As a result, I felt it was important to offer young people the chance to meet face to face and not simply talk on the phone. Bringing my experiences to the research helped to maintain the engagement of more than thirty young people, many of whom were quite vulnerable, in the research process over a period of three years.

Involvement varied throughout the project. Some young service users did not come to further meetings while others continued to be involved for up to three years. This was often due to circumstances dictating their ability and inclination to be involved in the project. Young service users with college work and childcare commitments were less able to attend meetings. I arranged some meetings in the evening to enable young service users with daytime commitments to attend project meetings. Some young service users experienced recurring mental health problems and family and relationship difficulties, during which their involvement was much reduced. For example, one young service user who was recruited through a youth psychosis service seemed to find it difficult to concentrate during the quality indicator development group (described below). Despite these issues, there was a core group of four to five young service users who were extremely committed to being involved. Throughout the data collection period I strived to maintain contact with each young service user via emails, phone calls and Christmas cards, regardless of their level of involvement. Figure 3 outlines the different stages of data collection and involvement throughout the entire project. Details of each stage are presented throughout this chapter.

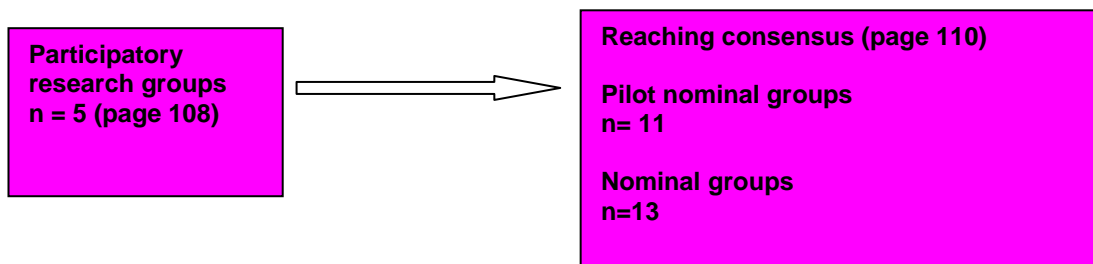
### Figure 3: Data collection and involvement

Key: blue = co-researchers from the original nine service user recruitment sites only; orange = participants recruited from focus group recruitment sites only; pink = co-researchers and participants recruited from both the original nine service user recruitment sites, additional 6 recruitment sites and focus group recruitment sites.

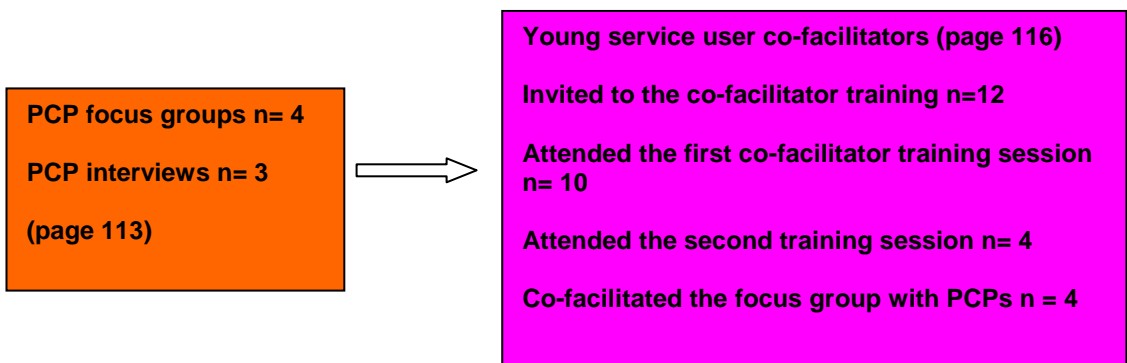
#### Stage 1) Focus groups and interviews with young people



#### Stage 2) Developing the quality indicators



#### Stage 3) PCP focus groups and interviews



## Co-facilitator training and involvement

I delivered the co-facilitator training alongside a senior collaborator (DR) who was also a mental health service user researcher. Thirteen young service users took part in the co-facilitator training sessions. These began with a short presentation on the role of focus groups in research. Young service users were then introduced to the role of a facilitator and co-facilitator by taking part in role-play exercises, following which they were shown the recording equipment. During the second training session young service users took part in a mock-focus group, each taking turns as the facilitator and co-facilitator using the pilot topic guide. The training sessions provided further opportunities for the co-researchers to get to know one another and share their experiences. The co-facilitators were also asked for feedback on the information sheets and the self-report form that would be used to establish a young person's experience of emotional distress. After each training session I sent letters to all participants thanking them for their contribution.

Eight young service users co-facilitated the focus groups with young people and four co-facilitated the focus groups with PCPs. One of the reasons this was fewer than those that had completed the training, was because of issues of availability when the focus groups were scheduled.

**Table 7: Number of young service users attending the first project meeting, taking part in co-facilitator training and co-facilitating a focus group by recruitment site**

<i>Service</i>	<i>Attended first project meeting</i>	<i>Attended Co-facilitator training sessions</i>	<i>Co-facilitated a young person's focus group</i>	<i>Co-facilitated a PCP focus group</i>
Two GP Practices	8	6	2	3
Four Child and Adolescent Mental Health Services	1	4 <sup>4</sup>	4	0
Student Counselling Service	2	2	1	1
Two Black Service user Groups	1	1	1	0
<b>Total</b>	<b>12</b>	<b>13</b>	<b>8</b>	<b>4</b>

<sup>4</sup> One young service user attended the first project meeting but three others were recruited between the first project meeting taking place and the training sessions resulting in four young service users in total attending the training sessions.

## **Focus groups and interviews with young people**

The next stage in developing the quality indicators was to conduct a series of focus groups and interviews with young people, co-facilitated by young service users. Before the focus groups took place, pilot work was undertaken to inform the process of data collection.

### ***Pilot focus groups and interviews***

The main objective of the pilot work was to identify the terminology used by young people to describe mental distress and to develop the topic guide. A secondary objective was to determine whether participants were more or less open about their views and experiences during a one to one interview compared to a focus group.

I thought it appropriate to invite focus group participants back for a second focus group (wave 2) to feedback the initial analyses from the first focus group (wave1). This is a form of respondent validation, which aimed to confirm whether participants were in agreement with my interpretation of what was said (Lincoln & Guba 1985). The pilot focus group was also set up to test the feasibility of asking young people to return for a second focus group.

Pilot focus groups were conducted with a group of sixth form students attending a summer school programme, young men from a homeless shelter and a group of students from a local university (see participant details in table 15). In order to incorporate the views of young Asian women into the pilot work I held an informal meeting with four young Asian women from a local Muslim Women's group. I also wanted to compare individual interview and focus group data to note any differences between the two methods of data collection. Individual interviews were conducted with two young people from a youth project and one from a homeless hostel.

I presented the pilot participants with a case vignette describing a young person with depression. When asked to explain the symptoms, participants repeatedly described the individual as 'stressed out' and 'depressed'. Other questions developed from the literature, the research question, and my own experience were included in the pilot topic guide and put to the participants.

Each pilot focus group was transcribed by a research administrator. I edited each transcript by listening to the recording and identified key themes.

Pilot focus group participants returned two weeks later for the second focus group (wave 2). Key themes from the first focus were presented and participants were asked to comment on whether they agreed or disagreed with my interpretations. The participants

remembered what they had contributed to the first focus group and provided detailed reasons for their views and opinions. This confirmed that respondent validation was an appropriate method to use with young people.

The results of the pilot work (detailed in the following chapter) prompted me to distinguish between topic guides for the first and second focus group (wave 1 and wave 2). The wave 1 topic guide was designed to introduce participants to the concept of mental distress at the same time as eliciting general views regarding help seeking and appropriate places for help. The wave 2 topic guide allowed me to probe further into the issues raised by participants by asking them to respond to each individual theme emerging from the initial analysis. Hence the aim of having a wave 1 and wave 2 focus group was to both modify the topic guide and enable respondent validation of the initial themes. See appendix one and two for details of the topic guides.

### ***Focus group participants***

Once the pilot work was complete, young people were recruited to take part in a series of focus groups about the appropriateness of primary care as a place for help with mental health problems. This thesis is particularly interested in young people who are difficult to engage in primary care and have a high prevalence of mental health problems compared to other groups. As a result the following groups were purposively sampled: homeless young people (Craig & Hodson, 1998), African-Caribbean men (Harrison et al. 1997) and Asian women (Bhugra et al. 1999; Chew-Graham et al. 2002). As the sample mainly comprised young people in education or out of work I also included a group of young people who were in employment to provide an appropriate comparison.

Community samples have been found to contain a significant number of participants who meet diagnostic criteria for psychopathology but who have not accessed services (Thurston et al, 2008). For that reason recruitment was not limited to GP surgeries. It was considered important to not exclude those young people suffering from mental health problems that had not sought help, had not had their problems recognised or who had used alternative services (such as drop-in centres, or a student counselling service). A sixth form college, a university, a hostel, a drop-in centre and a group of local employers agreed to advertise and invite young people aged 16-25 to attend a focus group to discuss mental health problems and the role of primary care services. As participants were recruited from the community, rather than from GP surgeries, young people self reported their experience of mental health problems using a form (see appendix three). Participant details are presented in the following results chapter.

### ***The focus groups and interviews***

The focus groups were facilitated by myself (TG) and co-facilitated by a young service user. We met beforehand and travelled together to the focus group venue. The young service users helped me set up the focus group recording equipment, seating and refreshments. Each group of young people took part in two focus groups (wave 1 and wave 2). The first focus group opened with a discussion about the reasons why, or why not, young adults seek help for mental health problems. A case vignette was used to generate discussion amongst the participants. Participants spoke about their own views and experiences of seeking help from primary care services including general practitioners, counselling services, and the role of medication. Finally, alternative sources of help were discussed, such as friends and family and non-medical services (see topic guides in appendix one and two). Both the co-facilitator and I took field notes.

The co-facilitator and I disclosed our experiences of help seeking to encourage the discussion (Zeller 1993). This established a feeling of trust and promoted sharing between co-researchers and participants. For example, when asked what impact this had, participants noted that it made them feel more comfortable to share their stories with others and that they appreciated the recognition that they were not alone in what they had experienced. The co-facilitator and I were also able to consider different questions during data collection that might not have been asked by someone without similar experiences. Having young service users as co-facilitators created a more youth-focused atmosphere as participants often directed questions specifically to the co-facilitators as opposed to asking me.

After each focus group, the co-facilitator and I held a de-briefing session to review the discussion and address any issues. Each wave 1 focus groups was tape-recorded, transcribed, edited and field notes added for context. I read through the transcripts and identified approximately twelve themes from each. Roughly two weeks later each focus group was repeated with the same participants (with the exception of the student group - see table 8). Initial codes from the first focus group were presented to the participants. Participants were asked to elaborate on why they had put forward a particular opinion. This generated further data as the participants added to and clarified their positions on the topics and discussed in greater detail (Bloor 1983). The second focus groups were tape-recorded, fully transcribed and supplemented by field notes taken by both myself and co-facilitators.



## Individual interviews

After the Asian female focus groups had been completed, two of the participants informed me that they did not feel comfortable talking about their own experiences with a group of people they already knew very well and whose families knew each other. This prompted me to arrange individual interviews with three of the focus group participants who reported experiencing a mental health problem. This generated richer data than had been collected during the two focus groups with young Asian females. This issue was not identified within any of the other focus groups and was not repeated outside of the Asian female group. As with the group discussions, the individual interviews were also tape-recorded, transcribed, and supplemented with field notes.

**Table 8: Focus group participation and retention**

<i>Focus group</i>	<i>Number of participants</i>	
	<i>In focus group 1</i>	<i>In focus group 2</i>
Students	8	6
Asian females	8	8
Sixth form males	7	7
Sixth form females	7	7
Hostel residents	8	8
African-Caribbean males	6	6
Employed	6	6
Total number of focus group participants	50	48

## **Thematic analysis and developing the quality indicators**

The next stage in developing the quality indicators was to allocate the focus group and interview data into coding categories (Boyatzis 1998). The data in each category was used to develop quality indicators by young service users involved in the project.

### ***Coding framework***

An initial coding framework was developed from the topic guide, issues reported in the literature, the pilot focus groups and interviews. As data collection continued, an iterative process was followed in which the initial coding framework was extended to include new themes as they were identified in subsequent wave 1 focus groups and interviews. Participants' agreement with my preliminary interpretations from the wave 1 focus group validated the coding framework (Lincoln & Guba, 1985; Bloor 1983; Reason & Rowan 1981).

### ***Multiple coding***

Two of the transcripts were read and coded by young service users and qualitative researchers from the steering group. Both of the young service users had taken part in the same focus groups (employed young adults) prior to undertaking the multiple coding exercise. One of the young service users had recently accessed both secondary and primary care services for her mental health problems. She had been educated at university, and had no prior experience of being involved in a research project. The second young service user had consulted a university counselling service a few years ago and had previous experience of taking part in a research project. The third member of the multiple coding team was also a member of the research team. She was a senior qualitative researcher (JM) with extensive experience of conducting primary care mental health research. The final member was a GP academic (HL) who was highly experienced in conducting qualitative primary care mental health research. Before coding the transcripts each analyst was presented with the coding frame and an explanation of each code. I met with each analyst to compare coding results and reach a consensus (Mays & Pope 1995; Bloor 1983). In particular, disagreements and alternative meanings in the data were highlighted and discussed. Barbour (2001) argues that rather than concentrating on the level of concordance between coders, what is of most importance when conducting a multiple coding exercise is the opportunity to debate and flesh out new and competing interpretations of the data and apply these to the process of analysis in a systematic way. The multiple coding exercise allowed me to explore new ways of interpreting the data by taking in the opinions of other researchers and young service users involved in the project.

This process also contributed to a new way of interrogating the data (see the example below).

### Example of how the discussions between co-researchers impacted upon coding

#### Extract from employed focus group 1

*R: What made you keep going back to those appointments then?*

*P5: I was forced practically at a time when my partner then was like oh your going to the counsellor no matter what you say and it was like ok fine so I'd just get up and I'd go and he was like if I couldn't get out of it then I'd go because he would actually follow me there its like he'd wait outside until I was finished he was like ok we'd sit there and we'd chit chat but it was not about the problem because I couldn't see how they would help me until I started talking to them actually.*

*R: Yeah.*

*Co-facilitator: She had to get comfortable.*

*P5: I had to know the person because it was like I don't know you your ok but with total strangers you can be whatever for all I know I don't know it was a matter of getting to know him and yeah they can understand my situation they most probably have had the problem but there's worse in a situation with other people.*

During the preliminary coding of this transcript, I coded this extract as 'counselling/neutral' as the participant was talking about her experiences and did not make any overtly positive or negative comments about the experience of receiving counselling. However, both of the young service users explained that they thought that the extract illustrated the importance of being able to relate to a health professional. Hearing young service users provide reasons for their interpretations of the data encouraged me to bring my own experiences of counselling to the analysis. I agreed with their rationale and was reminded of the importance of being made to feel comfortable by a health professional and so added a sub-code, 'relating to a health professional'.

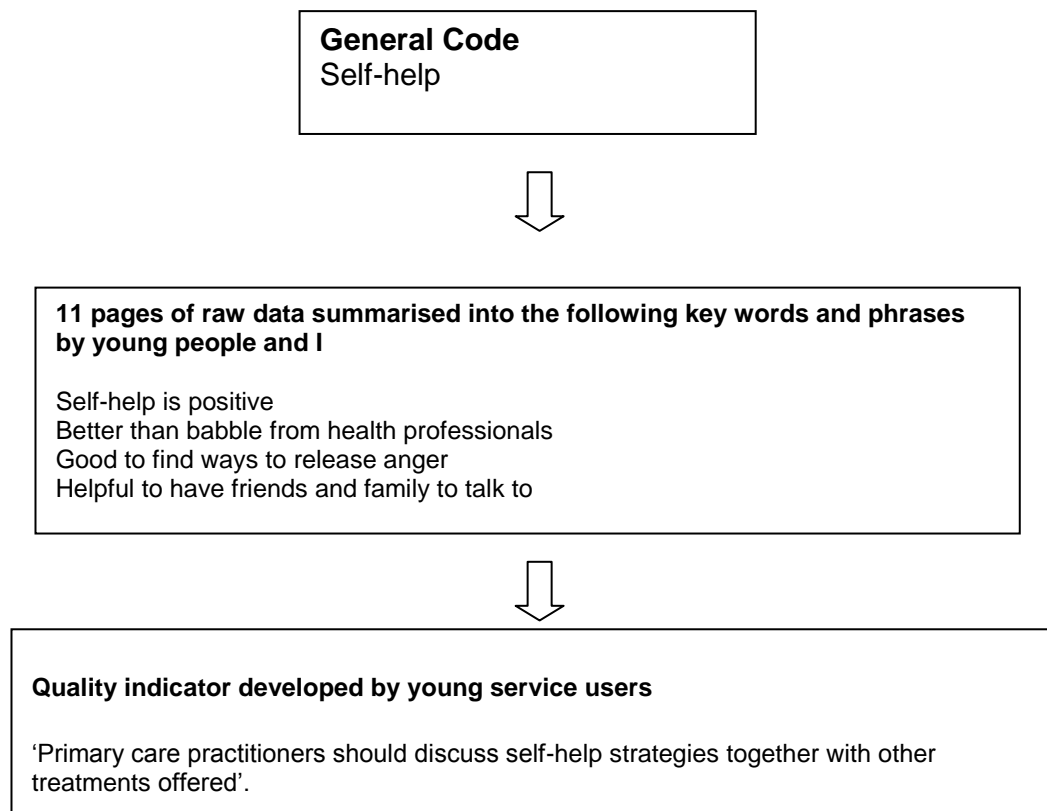
My own experience of counselling also led to the development of codes, such as 'reasons for not seeking help' (Mays and Pope 1995). The other analysts agreed with these codes during the multiple coding meetings. I continually scrutinised all the data contained within each code to ensure consistency. Each code had a label and clear boundaries that would illustrate the inclusion or exclusion of data into that code (Boyatzis 1998). The computer software package Win-Max (later upgraded to Max QDA) was used to systematically code, identify and retrieve data for the thematic analysis. The codes are presented in the

following chapter. A full thematic analysis of the focus group and interview data was conducted after the quality indicators were developed. This is also presented in the following chapter.

## ***Developing the quality indicators***

The next stage was to construct quality indicators from the focus group data. Two young service users, three GPs and I identified the codes that were most relevant to primary care which practitioners would be able to influence. These 13 selected codes are detailed in the following chapter. Five young service users attended two all day participatory research group meetings facilitated by myself and three senior researchers (DR, AT and JM<sup>5</sup>). The young service users were grouped into two pairs and assigned a facilitator. One service user was happy to work with only a facilitator and not another young service user. Each group was allocated a number of codes along with the transcripts containing the raw data. The young service users and facilitator read and discussed the data contained in each code. They were asked to summarise the data in the code into key words and sentences. I then grouped together similar key words and sentences. Each group of similar words and phrases was then returned back to the participatory research teams. Each team was then asked to develop each group of key words and phrases into a single quality indicator (see the example below).

**Figure 4: Example of how codes were developed into quality indicators for ranking by the Youth Expert Panel**



<sup>5</sup> DR and JM have been referred to earlier in the chapter. AT was a GP academic and principal investigator on the study.

**Table 9: numbers of young service users taking part in the research process by recruitment site**

<b>Service</b>	<b><i>Developed the quality indicators</i></b>	<b><i>Attended Pilot nominal group</i></b>	<b><i>Attended Nominal Group</i></b>	<b><i>Attended steering group meetings</i></b>
Two GP Practices	2	3	4	2
Four Child and Adolescent Mental Health Services	0	5	2	0
Homeless Shelter	1	0	0	0
Supported Housing Project	1	1	0	0
Early Intervention Service	0	1	2	1
Young peoples drug and alcohol support service	0	0	1	0
Adult Psychiatric Unit	1	0	1	1
Eating Disorders Website	0	1	3	0
Totals	5	11	13	4

## **Using the nominal group technique to reach consensus**

The next stage in developing the quality indicators was to ask young service users to reach consensus on which quality indicators of best practice were the most important.

Nominal group technique was used to calculate the level of agreement among young service users. The nominal group technique (Delbecq & Van de Ven 1971) is a formal consensus method that has been used in healthcare to examine the appropriateness of clinical interventions, practice development, education and training (Jones & Hunter 1995). Where evidence is insufficient and/or inconsistent, nominal group techniques have been employed to allow for a wider range of information to be synthesised (than is for the case when using statistical methods) by capturing the opinions of experts in the field under investigation. Participants are presented with a range of materials upon which they are asked to reach agreement. Agreement is calculated by successive rounds of either voting, ranking prioritising options or assigning specific values to quality indicators or a scenario (Murphy et al. 1998). Between each round the results are fed back to the group and participants are encouraged to provide reasons for their views. Participants therefore influence each other, and agreement is reached through group interaction.

The nominal group technique is not the only method of reaching a group consensus employed in health services research. For example, the Delphi technique uses survey methodology to ascertain the views of stakeholders on a particular phenomenon (Elwyn et al. 2006; Shield et al. 2003). Using this method, participants' views are collated in isolation of one another, discouraging interaction. The Delphi technique would not have enabled me to engage the young service users through group exercises. Encouraging group interaction was a vital component of the participatory methodology employed to involve young service users in the research process. Indeed, one of the functions of participatory research is that participants carry out tasks that they haven't previously undertaken, building their confidence and self-esteem in the process.

### ***Pilot Youth Expert Panel with young service users***

Before asking the young service users to decide which quality indicators were the most important, they were piloted with a Youth Expert Panel (YEP) of eleven young service users. Some of the YEP members were recruited from the focus group stage, others had been co-facilitators and one had been involved in developing the quality indicators (see table 9). The pilot YEP was invited to an all-day meeting (see the information sheet in appendix five). They were told that the purpose of the meeting was to edit and prepare material which would then be presented to a second group of young service users. The participants were not told how the level of group agreement would be defined or what the consequences of their rankings would be. The second aim of the all-day meeting was to test the feasibility of conducting a nominal group with young service users.

Each quality indicator was read out to the YEP as well as being displayed on a power-point slide. The panel was invited to comment on the clarity of each quality indicator. Clarity was defined as 'whether the quality indicator was easy to understand'. The pilot YEP was also asked to provide suggestions as to how the quality indicators could be improved. This process improved the validity of the quality indicators because they were amended on the basis of the young service users' experiences. Involving eleven young service users in refining the quality indicators also strengthened the methodology as the opinions of more than one young service user were taken into account. During the second part of the meeting, the YEP was asked to individually rank each quality indicator in order of importance on a 5-point scale (1 – very important, 2 – important, 3 – No opinion, 4 – Not important, 5 – Not at all important). Importance was defined as 'the extent to which they thought the quality indicator was important in providing what they needed when suffering from mental "distress"'. Traditionally, 9-point scales are used for nominal groups but it was decided that a 5-point scale would provide less opportunity for indecision and confusion. The members of the YEP often spoke their ranking out loud and explained why they held that particular view. The results of the first round of ranking were calculated, anonymised and fed back. The YEP members were then asked to re-rank those quality indicators upon which they disagreed and to give reasons for their rankings.



### ***The final Youth Expert Panel***

After work with the pilot nominal group had concluded, a new group of twelve young service users was recruited to become members of a second YEP for the nominal group proper (see table 9). The objective was to reach a group consensus on which quality indicators should be included in the quality indicators for Primary Care Professionals (PCPs). As with the pilot nominal group, the second YEP was asked to individually rank each quality indicator on a 5-point scale after each one was presented to its members. The YEP was informed that only those quality indicators with 'a high level of similar scores' would make it through to become quality indicators. The frequency distribution of scores from the first round of ranking was presented back to the YEP (Murphy et al. 1998). Members of the YEP gave reasons for their rankings and were asked to re-rank the quality indicators (second round ranking). Three senior researchers (DR, AT, JM) observed the group and kept a record of what was said to ensure completeness of data.

One week later, the same twelve young service users returned for a second all-day meeting. The objective was to present the results of the second round ranking scores and ask why individuals had changed their rankings between round 1 round 2. As is considered best practice, a distribution of the spread of scores was presented to the group (Murphy et al. 1998). Hearing convincing arguments put forward by other members of the group and seeing all the individual scores were given as reasons for changing scores between round 1 and 2 by YEP members.

### ***Reaching consensus through ranking scores***

Agreement on which indicators should constitute the final quality indicators was established by including only those indicators where all the individual rankings were either 1 or 2 (very important or important). The rankings were calculated from the round two scores to incorporate the impact of group interaction. As including outliers resulted in a very large number of final indicators, all outliers were excluded (Scott & Black 1991). The results were presented to the Youth Expert Panel and they all agreed that they were an accurate representation of their choices. The results are presented in the following chapter.

In summary, agreement was calculated using the following criteria:

- Scores from the second round of ranking
- Quality indicators with *all* scores either 1 or 2
- Exclusion of any outliers

The second aim of day two was to identify methods for assessing whether each quality indicator was in place in a primary care practice (Shield et al. 2003). The YEP was split into

four groups, with each group being given four quality indicators (which the group had agreed upon), and was tasked with generating methods of assessment for each one. Senior researchers from the research team (AT, DR and JM) and I facilitated each of these small groups. The groups decided which method(s) of assessment would be the most effective way to determine whether a quality indicator was in place and presented these to the nominal group.

### **Primary care professional's views of the patient-developed quality indicators**

To understand the strengths and weaknesses of the quality indicators and identify how they could be implemented in practice, a qualitative study was conducted. Sampling, data collection methods and participant recruitment will be presented. Details of how young service users were trained to be focus group co-facilitators will be explained followed by a description of the focus groups and interviews with primary care professionals (PCPs). Finally, details of how the data was subjected to a thematic analysis will be presented.

### **Sampling and data collection**

Mental health in primary care is increasingly managed by a multidisciplinary team of health professionals. Although the General Medical Services contract applies to general practitioners, in most services no one practitioner is the sole caregiver for a patient presenting with mental health problems. In addition, the National Service Frameworks and clinical guidelines are designed for a multidisciplinary audience of PCPs. For this thesis, multi-professional groups with a wide variation in special interests and practice size were purposively recruited.

Focus group methodology was used to capture the views of a wide range of PCPs involved in delivering care to young people. Focus group data was considered more useful than interviews because the aim was to understand why individuals would or would not incorporate the quality indicators into their practice. Using focus groups allowed me to explore agreements and disagreements between PCPs regarding the quality indicators (Crabtree 1993). In addition, reasons cited by participants in response to what others said and how participants changed each others opinions provided rich data regarding the way in which individuals made decisions and formed opinions (Kitzinger 1994). Hence, the reasons that individuals give in a one-to-one interview and a group differ significantly because in a group they are encouraged to provide justifications for their opinions and are often challenged by others. Using focus groups enabled the young service users to participate in data collection by acting as co-facilitators. This is an important function of the project's participatory design as all the young service users had only previously interacted with health professionals as patients.

Whilst maintaining that mental health is the responsibility of the entire practice team, there are significant differences between the time available and responsibility placed upon GPs relative to other PCPs. This is partly a function of professional training and expectations and the fact that some workers such as graduate mental health workers, if available, are performing a novel and largely untested role<sup>6</sup>. My aim was to hold a focus group with GPs to understand their specific concerns about youth mental health, but as only three of the six GPs recruited were able to take part three individual interviews with GPs from different practices were also conducted. The group with three GP participants constitutes a mini-focus group as there were less than 6 participants.

### ***Recruitment***

An initial set of interested practitioners invited their colleagues through emails and phone calls to take part (the snowballing method). Four 'lead PCPs' known to me through primary care research networks were identified. Each was invited to hold a focus group with the mental health team at their practice with lunch provided. For focus groups 1 and 2, I invited each participant to take part by email and phone, having been informed of their contact details by the lead PCPs. For focus groups 3 and 4, the lead PCPs informed their colleagues that a research project presentation and focus group discussion was planned to take place at their next meeting. None of the PCPs opted out. For the interviews, I emailed three GPs who were unable to attend the focus groups and invited them to an interview at their respective practices. All three agreed to take part. A majority of those who agreed to participate were interested in mental health issues. Practice details are shown in table 10 and 11.

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<sup>6</sup> Data collection was carried out in 2005. I acknowledge that graduate mental health workers are now being phased out and replaced by IAPT therapists. This will be covered in more detail in the discussion chapter.

**Table 10: Details of the practices at which focus groups were held**

<i>Practice/Focus group</i>	<i>Practice size</i>	<i>Number of 15-25 year olds registered</i>	<i>Mental health services available within the practice</i>
Practice 1 (Focus Group 1)	12,175	1,570	1. Counselling 2. Psychologist 3. CAMHS worker 4. CPN 5. GPCMHW 6. Assertive outreach
Practice 2 (Focus Group 2)	15,000	1,647	1. Counselling 2. Psychologist 3. Assertive out reach
Practice 3 (Focus Group 3)	14,123	1,787	1. Counselling 2. Psychologist 3. CAMHS worker 4. CPN 5. GPCMHW 6. Social workers
Practice 4 (Focus Group 4)	10,000	1,560	1. Counselling 2. Child/family psychologist 3. CPN 4. Benefit advisors

**Table 11: Details of the practice where GP individual interviews were held**

<i>GP Practice</i>	<i>Practice size</i>	<i>Number of 15-25 year olds registered</i>	<i>Mental health services available within the practice</i>
GP 1's Practice	10,500	884	1) Counselling/Psychologist 2) PCMHW 3) Assertive outreach
GP 2's Practice	7,200	653 (17-24 yr olds)	1) Counselling (waiting list closed) 2) Youth worker
GP 3's Practice	4,200	457 (15-25 yr olds)	1) Counselling 2) CPN

## **Co-facilitator recruitment and training**

Twelve young service users who had been involved in the project over three years were invited to co-facilitate the focus groups with PCPs. Two meetings were held over three weeks to prepare the young service users for their role as co-facilitators. They were offered £30 and paid travel expenses for each meeting. I sent a letter inviting the young service users to the first meeting followed by a phone call to confirm their attendance. One young service user was not available by phone and when contacted the other was not able to attend the meeting due to a hospital appointment. I called the remaining young service users the day before the meeting to confirm their attendance. Ten of the original twelve young service users attended. They had all met each other at previous meetings.

After presenting the quality indicators, I asked the young service users to work in pairs and discuss why each quality standard was important, using examples from their own experiences. Each pair was asked to present the main points of their discussion back to the group. They all talked candidly about their experiences with health professionals. Each young service user was asked to prepare a five-minute talk at home about his or her experiences and bring it to the next meeting a week later. The talk was to cover the following points: what happened when they went to see their GP; what was the outcome, how did they feel about the experience and would they go there again for a mental health problem. Each young service user also completed the demographics form which also asked for details about their own experiences of mental health problems and service use (see appendix three).

During the second part of the meeting, I presented the draft topic guide developed from the research protocol, the quality indicators and the issues reported in the literature. The young service users were asked to familiarise themselves with the topic guide and conduct a role-play as interviewers with a senior researcher acting as a GP (AT). The senior researcher was a practising GP with over twenty year's experience. The young service users were asked to ensure that the tape recorder was working and that the appropriate consent and forms were signed and completed by the interviewee. The interviewee was purposely negative about the quality indicators and expressed concern about resource and training issues for PCPs regarding mental health. This was to introduce the young service users to the variety of views held by PCPs regarding mental health in primary care. Afterwards, the group discussed the role-playing experience amongst themselves and with the GP and me.

Six young service users did not attend the second meeting: one had childcare commitments, three were not able to get the time off work and two were not comfortable speaking in front of a group of practitioners. As a result, four young service users attended

the second meeting. Each presented their prepared talks. I made suggestions on editing each talk so that a balance of primary care experiences was presented to the PCPs. The young service users were allocated to a focus group ensuring that they had not attended the surgery before or knew any of the PCPs at the practice. On the morning prior to each focus group, the co-facilitators met at my office to practice their presentations. We then travelled to the venue together. See table 12 for details of the co-facilitators.

**Table 12: Co- facilitator self-reported details**

<i>Gender</i>	<i>Age</i>	<i>Diagnoses</i>	<i>Use of Primary Care</i>	<i>Use of Secondary Care</i>
Female	21	Depression Anxiety Eating disorder	GP	Psychiatrist/CMHT
Male	19	Depression Alcohol/Drug problems	GP A&E	CAMHS
Female	21	Depression Psychosis	GP CPN	Psychiatric hospital
Male	25	Depression Psychosis	GP Counsellor	CMHT

### ***Focus group and interview format***

Each focus group (with the exception of the mini-focus group with three GPs) was facilitated by me and co-facilitated by two young service users. The mini-focus group was facilitated with one young service-user as the other was not able to attend that day. The groups were held between 1 and 2pm on a weekday at each practice with lunch provided, and each lasted 40-60 minutes. Each participant was given an information sheet and asked to sign a consent form (appendix six). They were also asked to complete a demographics form. Participant details are presented in the following chapter.

I began by introducing myself and the co-facilitator, and then provided a short summary of the project and the objectives of the group discussion. All participants were asked to agree to the group guidelines, which included treating everyone with respect and ensuring confidentiality. I gave a PowerPoint presentation on the development of the quality indicators. The co-facilitators then presented their experiences of primary care and read out

the sixteen quality indicators. The participants were given handouts of the slides to refer to and write comments on for the discussion.

I then began the discussion by asking if any of the quality indicators presented were already in place and if so to provide examples. Participants were asked if there were any quality indicators that they would like to be doing more of and which factors made it difficult to do so. The second part of the topic guide contained questions about the extent to which the quality indicators were realistic and what should be expected of primary care practitioners and services regarding young people's mental health. The impact of the General Medical Services (GMS) contract and the role played by Primary Care Trusts (PCT's) in relation to implementing the quality indicators was then discussed. Participants were asked to indicate which quality indicators would be relatively easy to implement and which would be more difficult. Finally, participants were asked to comment on the extent to which the quality indicators needed better definitions, as well as recommendations on how they could be incorporated into a toolkit for practices (see topic guide details in appendix seven). After each focus group the co-facilitators and I held a de-briefing meeting about the themes and issues raised during the discussion.

I conducted the individual interviews. The quality indicators were listed in a word document, which was emailed to each GP. I asked each GP to read through and make comments on each quality standard prior to the interview. Before each interview, GPs were asked to read the information sheet and sign the consent form. The same topic guide was used for the interviews as detailed below.

The focus groups and interviews were tape- recorded. An independent administrator fully transcribed each focus group and interview. I listened to the recording whilst reading each transcript to ensure they were verbatim. Field notes taken by co-facilitators and I were added to the transcripts and referred to for context.

## **Thematic analysis of data from primary care professionals**

### ***Developing a coding frame***

Data from the four focus groups and three interviews with primary care professionals were analysed thematically (Braun and Clarke 2006; Boyatzis, 1998). An academic GP (HL) and I read through the first transcript and noted key themes emerging from the data. These were added to an initial coding framework developed from the topic guide. As data collection continued, an iterative process was followed in which the initial coding framework was extended to include new themes as they were identified in subsequent focus groups and interviews. The final coding framework was then applied to two transcripts by the academic GP and myself to assess its consistency. We met to compare results and attempted to reach a consensus (Mays & Pope 1995). Any disagreements or inconsistencies were discussed and modifications were made to the coding framework (Barbour 2001). The data contained within each code was continually scrutinised by me to ensure consistency. The computer software package Max QDA was used to help manage the data and enabled me to systematically code, identify and retrieve data.

### ***Development of thematic networks***

Thematic networks were constructed to analyse the data (Attride-Stirling 2001). These are web-like illustrations that present the data according to three different levels of themes; basic, organising and global. Basic themes were developed from data in each code which illustrated similar issues. Close attention was paid to instances in the data where participants agreed with each other. Group agreement was defined as agreement between:

- Four or more participants in focus groups with six and seven participants
- Two or more participants in the focus group with 3 participants.

It was also important to include data sources other than group agreement because of the impact of group dynamics on what is said. Alternative viewpoints, disagreements and responses to being challenged were also used to develop the thematic network (Duggleby 2005; Kitzinger 1994).

The following steps were taken to account for undue influences of the group on members and vice versa, so that both the group and the individual could be the focus of the analysis (Kidd and Parshall 2000). Coding frequencies were used to initially identify groups that had



more or less discourse within each code. However, more emphasis was placed on the number of participants within each group contributing to the discussion, rather than the number of times data (which could have been from the same participant a number of times) was coded to that theme. In identifying the number of participants in a group that contributed to a topic of discussion, data from the each participant was included only once when interpreting the topic point. This method ensured that dominant members did not distort the analysis.

### Example of how codes were developed into basic themes

Codes	Issues discussed in coding meetings/ thought processes	Basic theme
Engaging a young person	They noted that a young person coming into contact with someone in a position of authority may impact upon the interaction. They were also aware that young people may judge a practitioner on how they communicate.	Engagement is difficult
Age differences	Participants were very aware of the age difference between themselves and young people and that this may affect how comfortable a young person may be	
Communication	Being comfortable talking to young people is important in the consultation	

Each basic theme was refined to ensure that they were both exclusive and broad enough to represent all the text segments associated within the theme. Table 13 illustrates the level of agreement, disagreement and data sources which made up the more frequent basic themes across the data set. Similar basic themes were grouped together to form organising themes illustrating larger shared issues. The name of the organising theme

represented the meaning of these shared issues. Moving from basic to organising themes required further interpretation of the data. Memos taken during the analysis were used to develop concepts from which organising and global themes were developed. The organising themes were clustered together to form larger global themes with the issues named.

**Table 13: Frequency of data sources for basic themes (analysis of PCP data)**

Key - \* denotes group agreement/ \*\* denotes theme developed through disagreement

<b>Basic theme</b>	<b>Data frequencies/sources</b>
Responsibilities of other sectors	FG1* FG2 FG3 FG4 GP GP3
Specialists vs Generalist roles	FG2 FG3* FG4* GP1 GP3
Implicit in practice	FG2 FG4** FG3 GP1 GP2 GP3
Difficulty of providing up to date information	FG1 FG3* GP1 GP3
Communication is problematic	FG1 FG2** FG3 GP1
Difficult to engage	FG1* GP1 GP3
Holding	FG2 FG3* GP2 GP3
Funding role of the PCT	FG2* (FG2**) FG3* GP1 GP3
Significance of QoF	FG2 FG3* GP1 GP3
Variation in demand for services	FG1 FG3* GP1 GP3

The thematic networks were presented to a young service user, a health service researcher (JM) and GP academic (HL). Interpretations were clarified and disagreements were resolved through changes made to the networks. Each thematic network was compared to the transcripts to confirm whether or not they were an accurate reflection of the data.

### Example of a memo extract

#### Memos used to develop the global theme 'examination of skills'

Memo title: Engagement is a skill  
Text: Focus group 2  
Author: Tanya  
Creation Date: 03/04/2006  
Linked to code: Engaging

Engaging – ability to engage a young person comes from having good communication skills. PCPs that feel able to interact and make a young person feel comfortable feel able to engage and hold a young person for longer have a more successful consultation or outcome.

Memo title: Confidence and attitude are linked  
Text: Focus group 2  
Author: Tanya  
Creation Date: 03/04/2006  
Linked to code: Attitudes

Attitudes – attitudes towards managing mental health problems in young people seems to be associated with which training opportunities are taken up by PCPs. This illustrates how confidence in managing a young person can be inconsistent.

Memo title: Examination of skills  
Text: Focus group 2  
Author: Tanya  
Creation Date: 03/04/2006  
Linked to code: Mental health problems are complex

The generic issues of managing mental health problems including the difficulty engaging young people and differences in attitude and confidence all come into play when managing mental health problems in young people – the quality indicators will examine whether or not PCPs have these skills.

## **Thematic analysis of data from young people**

The final study in this thesis consists of a further analysis of the focus group and interview data to develop a conceptual framework about young people's views on help-seeking for mental health problems, and the role of primary care within that framework.

### ***Rationale for a further analysis***

Twenty-six codes and sub-codes from the initial coding framework developed during the initial focus group and interview data analysis were not developed into quality indicators. This was because they were not considered to represent aspects of primary care that practitioners would have some level of control over and therefore should be assessed upon. However, these codes did represent concepts that could enrich and expand our understanding of young people's views on seeking help for mental health problems. An example of a code that was not included is "Reasons for not seeking help - admission of a problem". This code was developed from the research question (to understand and explore whether young people see primary care as an appropriate place for help with mental health problems). My own experiences of seeking help for emotional distress also influenced the development of this code. The following is an example of the content of the code:

#### **Sixth form females focus group 1**

*P1: 'Yeah because sometimes you, you know how you said about how you don't want to believe it yourself yeah there might be sometimes that like you know what you think your parents got an expectation of you and you've got an expectation of yourself...and you don't want to be seen in that time to be depressed because you want to be on top of it you want to be on the ball do you know what I mean'.*

*P3: 'Yeah, yeah because you want to deal with it yourself at first, you don't want to admit that you need help because you've done a lot for yourself already so*

#### **Sixth form males focus group 1**

*P3: 'That's all it is, some people just can't admit they're in the wrong, that they have a problem, innit, so that's why they avoid it'.*

A further example of a code that was not taken forward was "Relating/Talking to friends/siblings/cousins". Peer support from friends, siblings and cousins was found to be an important resource for young people. As there was also consensus in the literature about the role of friends and family as a preferred source of help for mental health

problems, it was considered vital to explore this data in a further analysis. An example of the content of this code was:

#### **Sixth form females focus group 1**

*'I think the only positive experience that I've had is just actually going to my friends do you know what I mean because how to if I was to go to a counsellor I'd feel stupid to be there do you know what I mean...'*

*(Female aged 16)*

*'I have to handle within my friends or within my family because I'm not the sort of person that accesses a psychologist or psychiatrist.'*

*(Female aged 23)*

#### ***Developing a thematic network***

Thematic networks were constructed to analyse the data (Attride-Stirling 2001) using the same principles presented earlier. Therefore, the following account focuses on any differences between the methods, rather than re-describing the development of the thematic networks.

Young service users had been previously involved in multiple coding meetings whereby focus group and interview data were allocated to codes. As described above, basic themes were generated by grouping similar codes together. Theoretical sensitivity was developed through engaging with the literature (in particular the work by Biddle and colleagues 2006) and my own experiences and those of the young service users who participated in the analysis (see the example below).

Group agreement was defined as agreement between:

- 4 or more participants in focus groups with six and seven participants
- Five or more participants in focus groups with 8 participants.

Table 14 illustrates the level of agreement, disagreement and data sources which made up the more frequent basic themes across the data set.

### Example of how codes were developed into basic themes

Codes	Issues discussed in coding meetings/ thought processes	Basic theme
wanting to deal with it on your own	Getting over it without having to seek professional help  I am strong enough to handle this on my own	important to handle the problem yourself
Ways of helping yourself	Agency of young people	
non-recognition of a problem/  reasons for not seeking help	Not wanting to disclose to anyone	do not want to admit there is a problem
non-recognition of a problem/  reasons for not seeking help	Do not feel that my experiences/feelings warrant attention from a health professional  Do not consider that you have a mental health problem	making a fuss
lack of confidence in services  mental health awareness	Do not know what they can offer  How can they change my circumstances?	do not believe that health services can help'

**Table 14: Frequency of data sources for basic themes (analysis of young people's data)**

Key \* group agreement/ \*\* theme developed through disagreement

AF – Asian females, BM – Black males, SFM – Sixth form males, SFF – Sixth form females, S – Students, E – Employed, H – Hostel

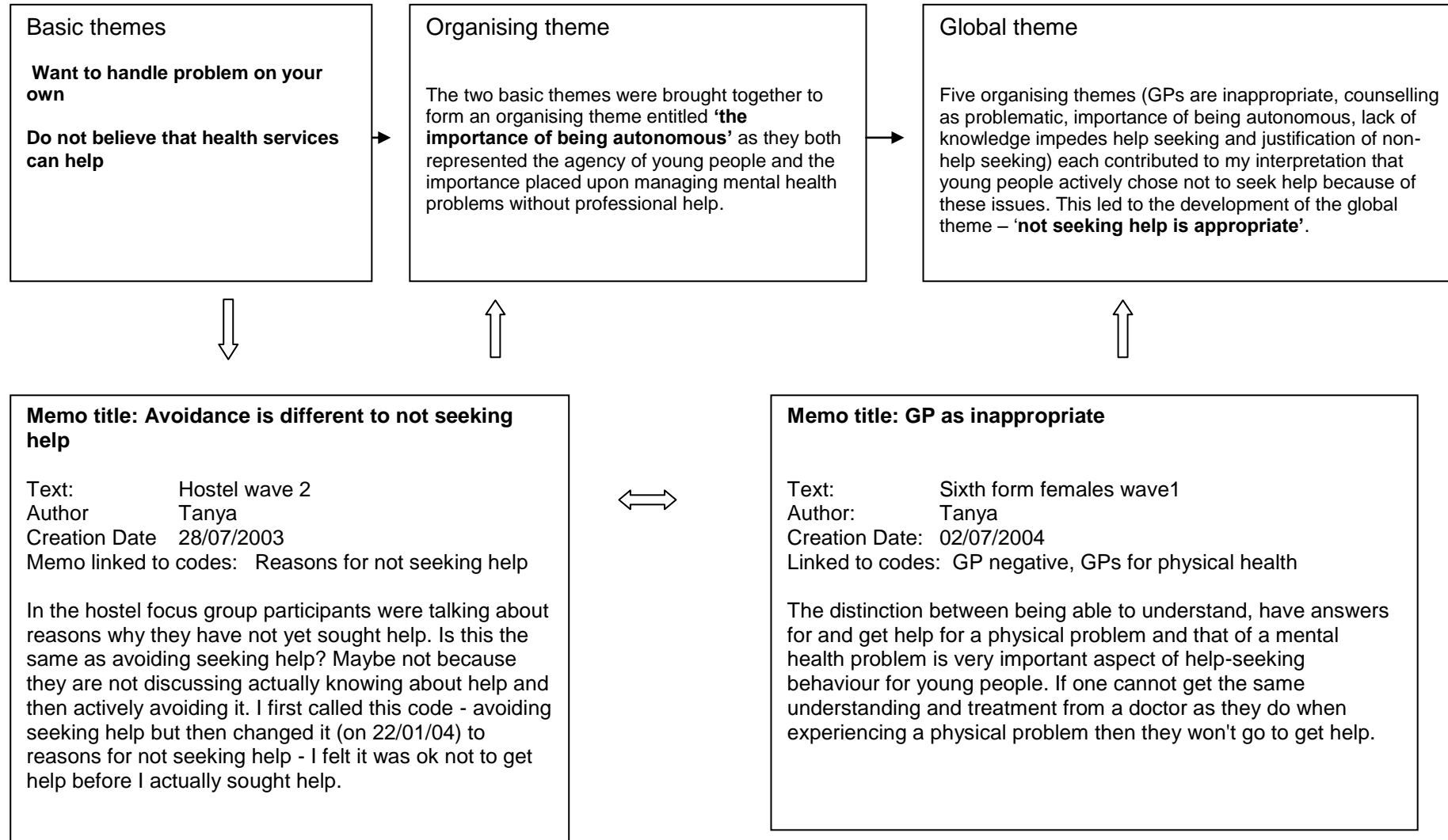
<b>Basic theme</b>	<b>Data frequencies/sources</b>
Want to handle the problem yourself	AF BM SFM SFF S* E H* Interview 1 Interview 2 Interview 3
Do not want to admit there is a problem	BM SFM SFF S E H* Interview 2
Need better knowledge about symptoms	AF SFM S* E* H*
GPs lack the time	BM SFM SFF S* E H
GPs can be unhelpful	AF* BM SFM* SFF S* E H
GPs for physical health	AF* BM* SFM* SFF* S* E* H*
Referrals are problematic	AF SFM* E**
Lack of meaningful interaction (counselling)	BM* SFM S H**
Sharing the problem with others	AF* BM* SFM* SFF* S* E* H* Interview 2
Peers are helpful	AF* BM* SFM SFF* S* E H
Cannot manage by yourself	BM SFM* SFF S E H
Acceptance of GP role and its limitations	AF, BM, SFM** SFF, E** Interview 1
Counselling is beneficial	AF BM** SFM SFF S E H Interview 2
Fear of being judged by others	AF* SFM* S
People with mental health problems experience stigma	BM* SFM* SSF* S E I2
Concern about side effects of medication	AF* SFM, S Interview 1
Questioning confidentiality	AF1* S* Interview 1 Interview 2
Do not trust that GP consultations are confidential	AF1* SFM* SSF* Interview 1 Interview 2 Interview 3

### ***The use of multiple coding meetings and memos***

Memos were written during the analysis. These guided the way that basic themes were grouped together to develop organising themes and subsequently how basic and organising themes were developed into global themes (illustrated in figure 5 below). I developed the thematic networks and asked two senior researchers (AT and JM) and two young service users to comment on whether they agreed with my interpretations. These meetings also generated new interpretations of how the themes were related to each other. Disagreements were discussed and changes made to incorporate shared interpretations between young people with experience of mental health problems, senior primary care researchers and myself.



**Figure 5: Example of the relationship between basic themes, an organising theme, a global theme and memos**



## Example of memo extracts

### **Memos used to develop the organising theme 'concerns about approaching close friends and family'**

Memo title: Talking to friends negative  
nds is an important resource but that it is often negative either you cannot trust them to keep it confidential, people think that you are being an attention seeker, they are actually accusing someone of being an attention seeker.

Memo title: Talking to friends/family negative  
Text: Focus Groups\Sixth Form Girls Wave 1  
Author: Tanya  
Creation date: 02/07/2004  
Linked to code: talking to mates/family

The negative aspect of going to friends and family for info and advice. This came up quite a few times in other transcripts. Although they are an important source of help seeking help from them is also risky as they are not able to be objective and there is a fear that they might 'judge you'.

**Memos used to develop the organising theme 'importance of approachability'**

Memo title: Doctors as your friend  
Text: Student wave 1  
Author: Tanya  
Creation date: 12/02/2003  
Linked to codes: GP\Language and interaction  
GP\positive

Twice participant has said of a good service and getting her needs met - 'they are not like doctors but are like friends'. As if to say a good doctor for young people does not act like 'doctor'

Memo title: Language and Interaction  
Author: Tanya  
Creation date: 04/02/2003  
Linked to codes: GP\Language and interaction  
Relating

There is a culture around being ability to verbalise a problem and there are also ways of interacting with a young person/adult that need to be captured in this study. These can facilitate doctors to interact with younger patients

Memo title: Religion  
Text: Focus Groups\Asian Wave 2 08.04.03.txt  
Author: Tanya  
Creation date: 02/05/2003

Important to relate to someone who will understand your predicament - if it is religious one.

Memo title: Complex needs  
Text: Sixth form females wave 1  
Author: Tanya  
Creation date: 12/02/2003  
Linked to codes: GP\Accessibility, GP\positive

She has complex needs and shows that the place that best meets those needs is a place that has all the services she needs in one place. So accessibility is not just about opening times and transport to get there but also about have her needs met on one place - treating her holistically.

## ***Summary***

This chapter presented a transparent account of how the research was conducted. I have presented the theoretical principles guiding the participatory approach that was adopted. Recruitment and involvement of young service users and their role as co-researchers has also been described. Focus groups with young people from community settings (both with and without mental health problems) were co-facilitated by young service users in order to generate data that was used to develop the quality indicators. Participatory research groups were adopted to facilitate young service users to work together, and with support from other more experienced researchers, develop the quality indicators. Young service users were recruited to join a nominal group tasked with reaching a consensus on which quality indicators were the most important. Young service users who had developed the quality indicators presented them to primary care professionals through focus groups. A thematic analysis of the focus group and interview data was conducted using a multiple coding team including young service users and senior researchers. A similar approach was adopted for the analysis of the focus group and interview data with young people to explore their experiences and perspectives on seeking help for mental health problems.

I have attempted to provide a full and detailed account of each of these stages. The goal was to illustrate the rigorous process of participatory research. By doing so I hope to have also shown that the level of abstraction has been raised by incorporating personal experiences into the research process.

## **CHAPTER FOUR: RESULTS**

This chapter will present results from the three phases of the study. The first section will present the results of the focus groups and interviews with young people. Although the full thematic analysis was conducted after the development of the quality indicators it is logical to present these results first to illustrate how the analysis impacted upon the development of the quality indicators. The second section will present the quality indicators. The final section will show the results from the focus groups and interviews with primary care professionals regarding their views of the quality indicators and will present areas of agreement and disagreement between PCPs and young people.

### ***Pilot work***

Pilot focus groups and interviews were conducted initially to inform the design of the youth focus groups.

### ***Pilot focus groups***

Three pilot focus groups and interviews were conducted with young people from a range of different backgrounds. Table 15 shows the demographic characteristics of the pilot focus group participants and interviewees. The findings from the pilot focus groups impacted upon the methodology in the following ways described below.

### ***Developing the topic guide***

Young people used terms such as 'stressed out' and 'depressed' when describing the symptoms of the individual in the vignette. This alerted me to the differences between lay and clinical terms describing mental health problems. In addition, participants also used the same terms when I asked them to describe any signs that identified someone who was experiencing a mental health problem. As a result the terms 'stressed out' and 'depressed' were then incorporated into the topic guide for the pilot focus groups.

During the pilot groups with participants aged 16-18, there were periods when participants were not very communicative and it was difficult to facilitate a debate. This prompted me to ask participants to give an example of seeking help for a mental health problem. This succeeded in encouraging the participants to expand their contribution to the discussion and as a result the topic guide included asking for specific examples as a prompt.

**Table 15: Pilot interview and focus group participants**

Age	Gender	Ethnicity	Occupation	Recruitment Site
<i>Interviewees</i>				
16	F	African	GCSE student	Youth Project
18	M	Caribbean	A Level Student	Youth Project
18	M	White	None	Homeless hostel
<i>Sixth form focus group</i>				
16	M	Mixed Italian/Slovakian	A level student	Summer School
17	F	Nigerian	A level student	Summer School
17	F	Nigerian	A level student	Summer School
16	F	Nigerian	A level student	Summer School
16	M	Black British	A level student	Summer School
<i>Homeless focus group</i>				
21	M	Phillipino	None	Homeless Night Shelter
19	M	Mixed White-Asian	None	Homeless Night Shelter
21	M	White	None	Homeless Night Shelter
21	M	Black-African	None	Homeless Night Shelter
<i>Student focus group</i>				
25	M	Portuguese	Student	University
19	F	Russian	Student	University
25	F	White-English	Student	University
25	M	White-English	Student	University

***Distinct functions of the first and second focus group***

I also identified a series of issues that the group touched upon, but did not resolve, during the course of the discussion. For example, there were instances when members of the group spoke of general practitioners (GPs) as not respecting confidentiality, but at other times during the group, members would say that GP consultations were confidential. I presented this conflict to the group during the second meeting and asked them to clarify their position. Discussing such specific issues in more detail provided richer data and a deeper insight into the issue of GP confidentiality from the perspective of young people.

### ***Sampling and recruitment: Including people with and without mental health problems***

The pilot student group contained participants both with and without experience of seeking help for mental health problems. One participant openly discussed her experience of depression, seeing a psychiatrist, and of being on medication. This may have prompted others to disclose their own experiences and views about mental health, as during the course of the discussion each participant spoke about a time when they felt distressed and what they had done to seek help. One participant stated early on in the discussion that she did not have a mental health problem, but then later disclosed that she had seen a psychotherapist and that she wanted to talk to someone about problems she was having. Rather than cause participants to feel uncomfortable and stigmatised, including people with and without mental health problems in the same focus group, prompted participants to be more open about their own experiences. In order to encourage participants to disclose their feelings and situations to the group, during the next phase of the study the co-facilitators and I also shared our own experiences of help seeking with the participants.

### ***Sampling and recruitment: Compatibility of the sample***

Participants from the homeless pilot group were 'rough sleepers' with particularly high support needs. The preliminary analysis showed that mental health problems for this group were intricately linked to drug use, unemployment, and contact with the criminal justice system. Although the student and sixth form group did discuss a variety of issues in connection with seeking help for mental health problems, the differences between the two groups were not as marked as they were for the young homeless group. This alerted me to consider that the help seeking process for young homeless adults with enduring drug problems and criminal behaviour is far more complicated compared to other young people that are more integrated into mainstream society. I decided that young people with experience of homelessness but with lower support needs would provide a more valid comparison across each of the groups. Thus young people from a supported housing facility were recruited for the focus groups during the next phase of the study.

### ***Sensitivity of the topic***

Mental health problems and help seeking can be problematic issues to discuss openly, especially for young people that have experienced mental distress. Although there seemed to be no clear differences between the openness of interviewees and focus group participants there were differences between the focus groups. The students and homeless pilot groups talked openly about the issues affecting them there were periods, especially with the sixth form pilot groups, when participants were not very communicative and it was

difficult to facilitate a debate. This prompted me to arrange preliminary focus group meetings in the next phase of the study in order to introduce the issue of mental health, together with the role of health services. The pre-meetings were to be held a week before the first focus group to enable the participants to think about the topic of discussion prior to taking part. They were also designed to give participants a chance to consider what they wanted to contribute and decide what they would be comfortable with disclosing in the group.

Meeting with young people prior to the focus groups provided an opportunity to collect information about each participant's experiences with mental health problems, their diagnoses and places they had accessed for help. In preparation for the next phase of focus groups I developed a form (see appendix three) asking for demographic information, experience of mental health problems, and services used. Each participant was asked to complete this questionnaire in private as well as meeting with me privately to confirm my understanding of the information they had provided. I also asked if they were comfortable discussing the information they had given within the group. This was an essential part of facilitating the focus group discussion.

### **The focus group participants**

Seven focus groups were held with young people from a wide range of different backgrounds. Table 16 shows the demographic characteristics of the sample. At the time of the focus groups, all but seven of the fifty participants (that took part in the first wave of focus groups) had visited their GP within the previous 6 months and in many cases that visit had been in the recent past. Twenty-one participants reported that they had experienced depression (see table 17). Eleven participants reported that they had sought help from a GP for mental health problems (see table 18).



**Table 16: Youth focus group demographics**

<b>Group/ Demo- graphic</b>	<b>Sixth Form Girls</b>	<b>Sixth Form Boys</b>	<b>Asian Females</b>	<b>Employed</b>	<b>Students</b>	<b>Hostel Residents</b>	<b>African- Caribbean Males</b>
Males: Females	All female	All male	All female	1:5	1:7	4:4	All male
Age range	16-17	16-17	16-17	21-23	19-25	19-25	16-19
Self-reported ethnicities	Black- Caribbean Black- African Mixed White	Mixed Black- Caribbean Indian Black- Caribbean Irish	Pakistani Burmese Guyanese Indian Indian- Pakistani	White Black- African Black- Caribbean	White Bangladeshi	Black- African Black- Caribbean Spanish Kosovan	Mixed Black- African Black Caribbean
Occupations	All studying for A levels	All studying for A levels	All studying for A levels	All working full/part time	All studying for degrees	Training Working Looking for work	Training Working Looking for work Other
Focus group setting	Sixth Form College	Sixth Form College	Sixth Form College	Research Institute	University	Hostel	Drop in service
Percentage with self- reported mental health problems	43%	28.5%	57%	50%	62.5%	75%	50%

**Table 17: Youth self-reported experiences of mental illness/symptoms <sup>7</sup>**

Symptoms/Classification	Number of young people
Feeling low	25
Stress	21
Depression	21
Tiredness	19
Sleep problems	13
Anxiety	12
Eating problems	8
Self-harm	5
Panic Attack	4
Obsessions	4
Phobias	3
Manic episodes	3
Attempted suicide	3
Other	3
Hearing voices	1
Substance abuse	1

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<sup>7</sup> There were 50 participants in total. Some participants had more than one problem.

**Table 18: Youth self reported services accessed for a self-reported mental illness/symptom**

Symptoms/Classification	Number of young people
GP	11
Counsellor – Other	11
Other	8
School service	6
Drop in	6
Counsellor via GP	2
Student services	2
Psychiatrist	2
Accident and Emergency	2
Group Therapy	1
Psychologist	0

### **Young people’s views on seeking help for a mental health problem and the role of primary care**

The thematic analysis resulted in the development of three global themes; not seeking help is appropriate; help seeking as functional and help seeking as risk.

#### **Global theme: Not seeking help is appropriate**

Not seeking help was considered to be an appropriate course of action because of the following organisational themes: importance of being autonomous; non-help seeking is justified; lack of knowledge impeded help seeking; GPs are an inappropriate source of help and counselling as problematic (see figure 6).

#### ***Organisational theme: Importance of being autonomous***

Two groups agreed that it was important to handle mental health problems on your own<sup>8</sup> (Hostel and Student groups). This theme was also considered important by a minority of

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<sup>8</sup> Text that is underlined refers to basic themes in the thematic network.

participants in all the other focus groups. Some participants felt strongly about wanting to be in control of their lives. They spoke about exploring their independence by making their own decisions about how to manage stress and risk factors in their lives:

**Hostel focus group 1**

*P4: That's why that's why I think I keep it to myself because I think that I'm the only one that has my own solution but if its in my head and its getting to me or whatever its just going to have to get to me until I realise a solution.*

A minority of participants in five different groups believed that health services would not be useful (Hostel, Employed, Sixth form females, Asian females and Black males):

**Hostel focus group 1**

*P4: The reason why I would not is because I don't like I don't believe that anyone could do anything for me*

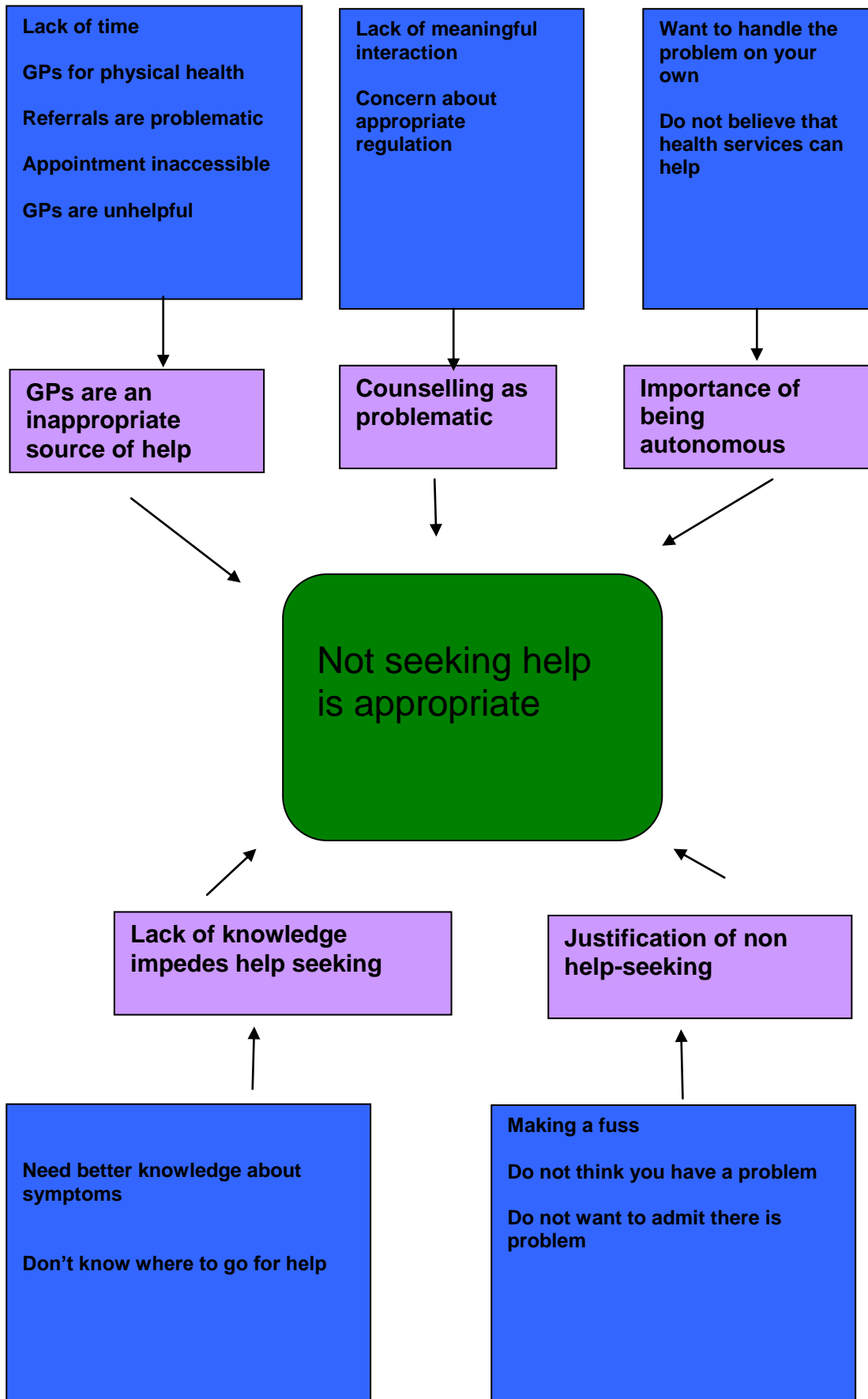
*P8: Yeah*

*P4: I would be if I told them my problems I'm thinking now hold on I'm telling them my problems but what can they really do? What can I don't just believe that they can do anything.*

As detailed in chapter 3 group agreement was defined as:

- 4 or more participants in focus groups with six and seven participants
- Five or more participants in focus groups with 8 participants.

Figure six: thematic network 4 - Not seeking help is appropriate



Employed participants felt that it was important to believe that the person you are seeking help from can help you and to have some knowledge of what the service can offer you.

#### **Employed focus group 1**

*P4: I think it's also important to believe that the person you're getting help from can help you.*

*R: Yeah.*

*P4: Because if you were like for me I was pretty convinced that this was just because I was a finalist and because I'd moved back to New York and because everyone around was so upset about what was going on in the world and I didn't really think that anyone could help with that so I had to that was the first hurdle that I had to get over it was actually maybe someone can help with this and maybe there would be value in going to seek help or to get help.*

*P5: Must have been tough in New York*

*R: Does everyone agree with that?*

*P3: I think for me it was the matter of like how can this person help me?*

#### **Organisational Theme: justification of non-help-seeking**

The Hostel group agreed that it was difficult to admit to having a problem as did a minority of participants in all the other groups except Asian females. This theme was also supported by one of the interviewees (Asian female 2).

#### **Black males FG1**

*P1: Admitting that they're in the wrong or that they have a problem*

*P5: It's true because if you have little conversations with people, like, everyone thinks that they're in the right - so I think 'oh I have no problem, there's nothing really wrong with me, maybe it's like I'm having a bad week' so people don't want to admit to when they're wrong or they need help*

Sixth form females agreed that young people seeking help for a mental health problem may feel that they are making a fuss about nothing:

**Sixth Form Females focus group 1**

*P6: I feel like I'm wasting time because I know how hard it is to get a doctors appointment.*

*Yeah.*

*P6: And then talking about stress I'd be like oh I am taking someone else's place someone that really needed the appointment.*

*P1: Someone like in the surgery coughing up their lungs!*

Some participants felt that seeking help would be a waste of time (All groups except the Hostel group). One participant in the Employed group disagreed with others in the group who felt that help-seeking was a legitimate course of action by explaining that she felt that emotional problems were an integral part of life and that it would not be something that one should discuss with a GP. One participant in the Asian female group offered an explanation of her opinion to the rest of the group:

**Asian female focus group 1**

*R: Does anyone have a different experience has anyone had a positive experience of counselling or?*

*P8: I think the only positive experience that I've had is just actually going to my friends do you know what I mean because how to if I was to go to a counsellor I'd feel stupid to be there do you know what I mean it would just be like ok.*

*P7B: I wouldn't actually tell anyone I wouldn't say I was going to a counsellor.*

*P8: I wouldn't go myself because I'd be embarrassed to go.*

*R: Really?*

*Yeah.*

*R: What do other people think about that?*

*P4: I think a counsellor - to go to a counsellor your problems need to be serious.*

*R: Yeah.*

*P4: So that's just like the connotation you get so if you went to a counsellor just say because you weren't happy you'd feel silly you'd feel like why am I wasting your time I haven't got problems sort of thing.*

*R: Yeah.*

*P4: But you have.*

### **Organisational theme: Lack of knowledge**

Three groups agreed that young people lack knowledge about mental health problems and some also felt that they did not know where to seek help (Employed, Hostel and Student groups):

#### **Student focus group 1**

*P4: A lot of these symptoms I wouldn't know about if I hadn't experienced them so the fact that they're not publicised and they're not written about and you don't read about them know about them makes you less aware of the fact that there might be a problem.*

Some participants were concerned that young people do not know where to go for help (Employed and Student and Sixth form male group).

#### **Employed focus group 1**

*P5: ...I said to him was that with mental health problems like if you have a pain in your leg you don't wait for your leg to drop off before you go to the doctor you know you like you go to the doctor fairly straightaway and say yeah I've got this pain and I don't want it to get any worse so you know here I am what can you do about it but like with mental health problems because people don't know where to go or don't know how to go about it or is scared of it you literally wait for your head to explode before you do anything about it...*

### **Organisational theme: GPs are an inappropriate source of help**

This theme illustrates the way that GPs are perceived by some young people regarding their role in treating mental health problems. This theme was made up from five basic themes: lack of time; GP appointments are inaccessible; GPs are non-specialists; negative views about referrals and GPs are unhelpful.



Students agreed that there was a lack of time with GPs (see page 124 for details on how group agreement was defined). This theme was also supported by a minority of participants within all the other groups except the Asian females.

### **Student focus group 2**

*P4: The biological stuff is different to the psychological stuff though isn't it in the sense that they can't prescribe something psychological until they've spoken to you and it takes time which they haven't got to which they haven't got.*

Some Asian females were concerned that it was difficult to access an appointment with a GP:

### **Asian Females focus group 1**

*P8: You think that they're going to give you the appointment straight away so you have the confidence to do it then but then if it's like next week the you can't be bothered.*

*P5: Then you start doubting why you're going in the first place.*

Three groups agreed that GPs can be unhelpful when seeking help for mental health problems (Asian females, Students, Sixth form males). This view was also put forward by a minority of participants in the remaining four groups. In two of the groups, the Black male participants in particular felt that GPs would be unhelpful for a young person experiencing mental health problems (Black males, Hostel, Sixth form females, Employed). Unhelpfulness was characterised by the following aspects: prescribing medication only; not being listened to and being dismissive. This view was also put forward by a minority of participants in the remaining four focus groups and by one interviewee (Asian female Interview 1).

### **Interview 1 (Asian female, aged 17)**

*He didn't really. I went in and I said oh I'm suffering from really bad headaches and I'm feeling really tired all the time I cant I'm not interested in anything anymore and he was just like oh have you got exams coming up and I was like yeah he goes oh its just stress of exams you know you'll get through it just make sure you work hard and I was like ok and he goes oh I can give you some tablets you can take when you get a headache and he gave me like a little book to write down what I eat to see whether it was anything I eat but I knew that it wasn't it was just basically because I was just really down and I just didn't want I don't know it was like I didn't want to go on anymore because I didn't know what I was going to do I was just fed up with everything but he didn't seem to understand.*

All seven groups agreed that GPs were associated with help for physical health problems and not mental health problems:

**Sixth form males focus group 1**

*P3: Doctors are just there for physical problems if you want to talk to someone go to a psychiatrist or whatever.*

*P2: A counsellor.*

*P1: Yeah exactly.*

*P3: What can doctors do they prescribe you they give you prescriptions nothing for mentally like or emotionally they give it to you for like physically say your head hurts or something you cant tell them oh well I'm going through this what can I do but like he L said like he was having trouble breathing they gave him an inhaler didn't they to help him stop how he was feeling just helped him to calm down.*

*R: They went to the physical to the like physical side yeah.*

*P3: Yeah that's true actually.*

Some young people were unhappy about being referred by the GP. In particular, Asian females were concerned about travelling to some distance from home to attend a referral. Sixth form males agreed that being referred felt like being dismissed. However, GP referrals were also considered necessary and were accepted as a normal part of general practice by others in the sixth form male group and employed group.

**Sixth Form Males focus group 2**

*P2: It's not so much helpful if you go to them in the first place to get help and then they just pass you on so that sort of like dents your ego as well sometimes because its hard enough turning to them and when they say no we ain't going to help you go to them it starts all over again.*

*R: Right so it's a case of you sort of get passed on and passed on.*

*P2: Yeah and then you have to build up the confidence to go to that new person again they'll probably refer you on as well.*

### **Organisational Theme: Counselling as problematic**

The term 'counselling' encompassed a wide range of one-to-one interactions between young people and professionals. Participants talked about conventional methods of counselling, speaking to key workers, and having a 1-2-1 with a youth worker. Others talked about being with a psychiatrist as a form of counselling. Black males agreed that there was a lack of meaningful interaction during the counselling process. This basic theme was also supported by participants in three other focus groups (Student, Hostel and Sixth form males).

#### **Black males focus group 1**

*P1: Because I had a bad experience with a counsellor when I was eighteen and I vowed never to go back again. She just sits there and I'm talking and I'm crying and all she was doing was looking at me and 'um hm'*

*P6: that's what my one was like*

*P5: that's the ones that just do it for the money*

*P1: she didn't give me no advice*

*P6: but with those kind of counsellors, is sometimes is that they don't understand or some of them it's like they don't want to get involved*

*P5: Did you have to pay for it though*

*P1: No*

*P6: my counsellor, I would go there yeah and she would have invite me to an interview and then ask me what's been going on and just be bear writing ('bear' - slang for that was all she was doing) she won't stop like to ask me to talk to her she just asks me to explain myself and just bear writing and that's it.*

*P5: yeah, most counsellors are like that - that's the ones that are in it for the money, they really experienced nothing deep so they can't really relate to what you're saying at that moment.*

Some participants in two groups felt very strongly about the lack of interaction with counsellors and this dominated the discussion until the facilitator was able to move onto another point (Hostel and a Sixth Form Male group). These participants were frustrated with the methods used such as going into detail without a response. Participants in the hostel group disagreed with others in the group (who were positive about the role of counsellors) by suggesting that counsellors only listen therefore do not come across as caring.

#### **Hostel focus group 1**

*P7: The GPs no really but there are counsellors that can.*

*P8: That's what I'm saying if.*

*R: Finish what you're saying.*

*P7: Yeah they I mean they can advise you I mean teach you ways how to you know how you how to do say it look inside yourself and see what's wrong, what's causing the problem.*

*P8: Or or*

*R: Hang on one at a time.*

*P8: Sorry*

*P5: Yeah I wouldn't I'm not very sure if they can help some they can some they cannot help but I seek the help I went to a counsellor I didn't go there just because I thought he was going to help me I went there because I'm alone I'm by myself here so you always need someone to talk to and hey it is their job they have to listen whatever you want to say they have to listen.*

*P3: Yeah.*

Later in the discussion

*P5: About the same thing. So they have to listen they get paid for it they have to listen to you even if you are telling them the same sentence all the way along they have to listen to you.*

*P7: That's my problem they have to you understand that's the whole point it's like they don't really care there getting paid to listen.*

*P3: It's their job.*

*P6: I know so that is not good enough for me*

*P3: No that is what I am saying*

*P7: To comfort me. I don't feel like there helping me because there doing it because they have to.*

*P3: Yeah.*

*P7: So they could be sitting there.*

*P5: No they don't help.*

*P7: Be somewhere else and just mmmm. Mmmmm. (Nodding)*

*P3: Listening because they're getting paid to do it.*

It is important to note that many of the same participants that were critical of counselling also felt that counselling could be helpful. For example, one participant in the student group said that counselling was negative because '*he would over-think things*' and also positive because '*it stopped me being anxious*'. Black males and one participant in the Sixth form male group were also both positive and critical of counselling.

Some participants from the Student and Black male groups were concerned that counsellors were not appropriately regulated:

**Student focus group 1**

*P3: regulated - there are so many ... anyone can set themselves up as a counsellor can't they?*

*P5: yeah, as far as I'm aware*

*P4: don't they need specific qualifications?*

***Not seeking help is appropriate: Group differences***

Young people living in a hostel strongly endorsed the notion of independence illustrated by their level of group agreement within the theme 'the importance of being autonomous'. The Employed, Student and Hostel groups all agreed that young people lack knowledge about mental health problems and some also felt that they did not know about sources of help.

The concern that GPs are inappropriate to help young people with mental health problems appeared to be especially important for Asian females. They were the only group to feature in all three of the following themes: GPs can be unhelpful, GPs are for physical and not mental health problems, and being referred is undesirable. The problems associated with consulting a counsellor were particularly salient for Black males. This group both agreed that there was often a lack of meaningful interaction with counsellors and questioned how they were regulated.

### **Global theme: Help seeking as functional**

Seeking help for a mental health problem was also considered to be useful. This global theme is made up of the following organisational themes: when self-reliance is no longer enough; personal relationships as first aid; GP and counselling services are useful; importance of approachability and lay knowledge is diverse (see figure seven).

#### ***Organisational theme - When self-reliance is no longer enough***

Although some young people wanted to manage mental health problems on their own, at one point all the focus groups and interviews considered that there was a point at which this course of action may become unfeasible. Sixth form males agreed that young people seek help because they cannot manage by themselves. In the Black male group, one participant said he would not want to seek help but handle his problems on his own, but this was met with dissent from three participants who advocated the importance of disclosing to others and sharing problems. This view was also put forward by some of the participants within all the other focus groups except the Asian female group:

#### **Black males focus group 1**

*P4: I don't know sometimes, everyone's different, like me, now, when I'm stressed, yeah I want to be alone, I can't be around people, I can't I have to be alone to think myself, like I can't have contact with people like - I can, but don't get me wrong but everyone seems annoying to me, I don't want to talk, or when they ask me a question, I'm aggressive, like, don't ask me nothing, I'm rude the way I answer, you get what I'm saying?*

*P1: But thinking and talking to yourself don't really help neither man*

*P4: mmm?*

*P1: Thinking and talking to yourself don't help because*

*P4: Not talking to myself, I just, sometimes I like being alone, for some reason it lets me think and I can think about how to solve my problems isn't it? Like when I'm around people I get so much different opinions man, it's not needed*

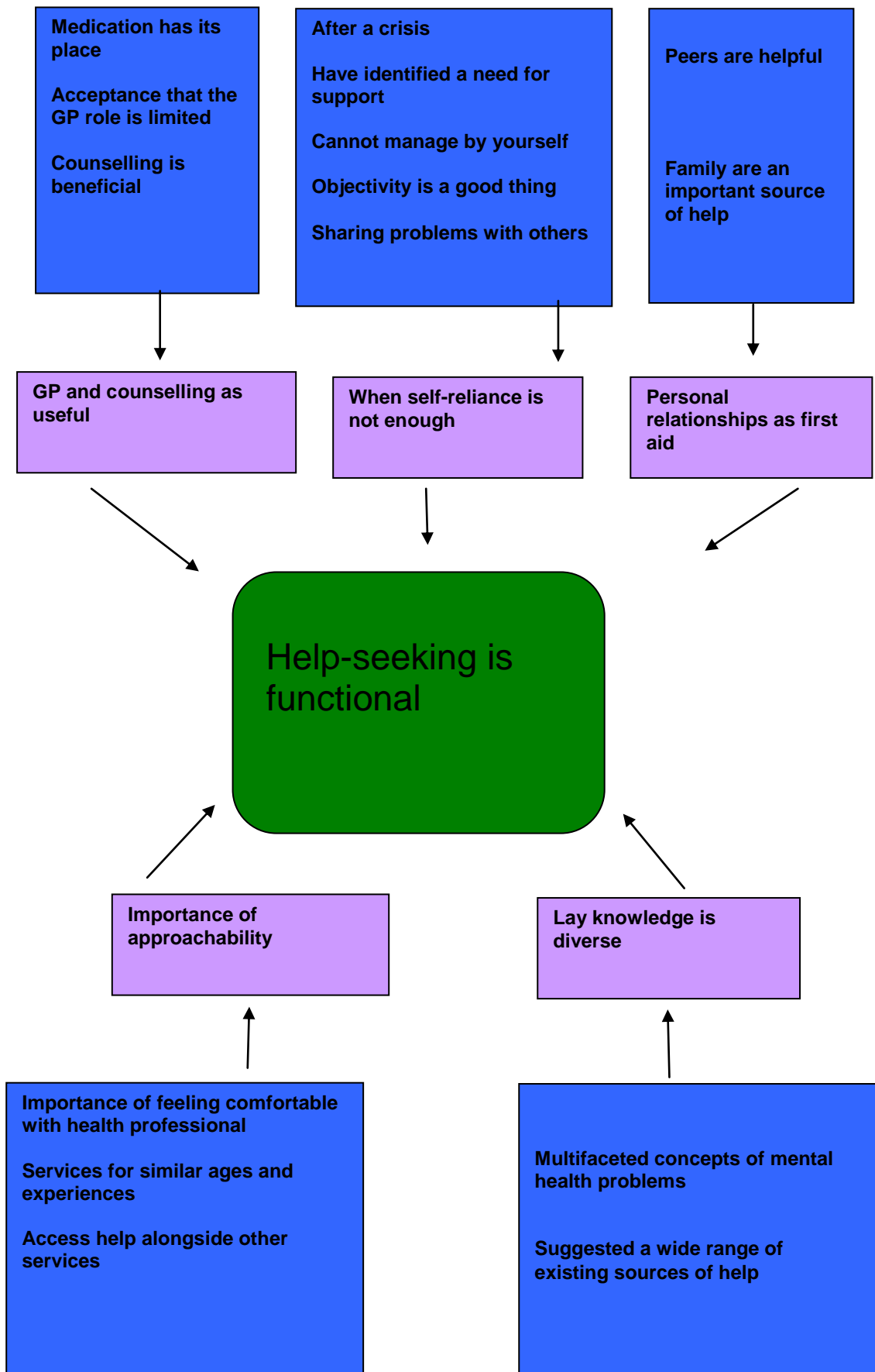
*Youth worker: What if you can't solve the problem yourself?*

*P4: But I'm sure I can*

*P1: You're sure?*

*P5: It is impossible to be sure*

Figure seven: thematic network 5 - Help seeking as functional





A minority of participants in three groups felt that reaching a crisis is often a precursor to seeking help (Employed, Student and Black male groups). Participants defined a crisis as a definable moment or series of events leading to a young person being in danger to themselves or to others. Some Black males associated help seeking as a way to avoid 'doing something to yourself or to someone else'

#### **Employed focus group 1**

*P2: ...I had a disagreement like with my friend's friend over something quite stupid and I was really off my like high on ecstasy and basically I've sort of thought of I might as well tried to take my life basically I slashed my wrists. When I went to the hospital the doctor had, had it in his head that I wasn't sort of a serious case that needed to be dealt with. Then he wanted to go off and deal with somebody else if it wasn't for the fact that my friend said look my mate has just tried to kill himself he needs to be sorted out now he realised sort of when he sort of bandaged me up and things. He was like you need to see a psychiatrist but I didn't feel that I needed to so I just refused after I was released from the hospital. I sort of went to my GP who automatically said well you are depressed and gave me a dose of like Prozac which after a week of taking it I just, just didn't feel like doing anything and it was like I sort of realise now that it was sort of a cry for help do you know what I mean?*

Some participants felt that help seeking occurred as a result of identifying one's own needs for help. The two female groups agreed that young people may want to be reassured or get advice (Sixth form females and Asian females). This was also mentioned by a minority of participants in three other groups and one interview (Black males, Student, Employed and interviewee 1).

#### **Sixth Form Females focus group 2**

*P5: I think you as a person need to decide when you need to go and see someone because if someone just saying look something is not wrong with you but as Sa said you could be in denial and you'd be like no, no I'm fine just a bit down but you as a person you should go look like Sa your down you need to go and talk to someone about it do you know what I mean so other people they could like give you advice and maybe that advice would make you think about you having to go and see someone but you have to actually say go and talk to someone or go and see someone.*

All seven groups agreed that sharing problems with others was something that young people with mental health problems should do. Sharing problems with others was also advocated by one interviewee (Asian female Interview 2).

### **Hostel focus group 1**

*R: What should she do?*

*P1: Get some help.*

*P3: She should come and see me. [Group laughing]*

*P4: I don't know.*

*R: What should she do she should get help what kind of help we talked about this before?*

*P1: Psychiatrist.*

*P3: No.*

*P4: She needs to talk to someone.*

*P3: She should just talk to some.*

*P7: Talk to someone.*

*P3: Yeah it's all about letting it out.*

*Group: Yeah.*

*P3: Because when you let it out yeah it's like releasing something you find you yourself will notice when you've got a problem and you.*

*P4: No you know what it is.*

*R: One at a time.*

*P4: It's a matter of finding someone that you can talk to.*

*P3: True.*

Sixth form females agreed that it was beneficial to seek help from someone who is objective. This theme was also supported by a minority of participants in all the other groups except Black males:

**Sixth Form Females focus group 1**

*P5: Yeah maybe someone whose not connected directly with you as a person like someone who's just totally out of it.*

*P1: Yeah so you can get an unbiased opinion.*

*Yeah. (Group)*

*R: So like someone who's not in your network?*

*Co-facilitator: Yeah not like a family member or a friend.*

*P5: So you know that it's a completely honest opinion or perception*

*P2: It's easier for someone that knows you to judge you really quickly as if it was someone that you didn't know they wouldn't be so judgmental.*

**Organisational theme: Personal relationships as first aid**

Personal relationships were considered to be hugely important. All of the groups agreed that close friends were an important source of help for mental health problems except the Hostel group. Three participants in the Hostel group felt that it was important to confide in friends.

**Sixth Form Females focus group 1**

*P2: I talked to (name of P1). (Name of (P1) is always a great help I think its better when you do talk to friends in your own situation but then I found it helpful when I spoke to like my sister she's older than me she's been through like school and everything like that so she's obviously gone through things like that so I just talk to her about it and cause I prefer talking about my problems it kind of goes away makes me feel better.*

Parents were also considered to be an important source of help. At least one participant from six of the seven groups and all three interviewees felt they would want to inform their parents of any difficulties. The hostel group however, did not site parents as a source of help.

### **Student focus group 1**

*P4: I was just going to say I'm not like that because I don't know what's on offer and if I needed some information, I'd ring my parents rather than go round college because I haven't got a clue.*

### **Organisational theme: GP and counselling services are useful**

Although participants felt that GPs and counsellors were inappropriate they also felt that they were useful. A minority of participants from four groups accepted that GPs have a limited role when managing mental health problems (Black males, Sixth form males, Asian females and Employed groups). In response to a discussion about counsellors having more time and GPs lacking mental health training, three participants in the Employed focus group provided contrasting opinions in support of GPs limited resources and large workload:

### **Employed focus group 1**

*R: Yeah ok what's the difference between a counsellor and a GP then?*

*Co-facilitator: A counsellors got more time for you*

*(Laughing in agreement)*

*P1: They listen. It's a very important factor about counsellors that I know of they listen.*

*P2: They don't judge.*

*P1: Thank you.*

*R: Don't just do people agree with that?*

*P5: Yeah.*

*Group Yeah.*

*P5: Although I think its very easy to be very harsh on a GP and I think I couldn't conceive of doing a GPs job like getting through the doorway however many people they see in a day with all the different ailments and illnesses that they see and have to deal with you know ok so they might give people with mental or emotional problems a short shrift but to be perfectly honest do you know what I mean like give them a break you know they've got a tough job.*

*P6: Having had just very limited training.*

*P5: Yeah exactly.*

*P5: It's hit and miss as well I mean you get some GPs that are really incredibly good and I've had you know two really positive experiences like my GP at home and my GP at university both of them were absolutely sterling in their response and yes ok they might have been only equipped to hand me a packet of pills but to be perfectly honest with you at least they did something they didn't just tell me to go away or get over it or whatever I mean I've heard of people having experiences of that I was lucky.*

A minority of participants in two groups accepted that a significant part of the GP role was to provide referrals to specialists (Employed young people and Sixth form males). This theme was developed in part, from a group disagreement within the sixth form male group. During the earlier part of the focus group a majority of participants agreed that being referred by a GP felt like being dismissed but later in the group one participant expressed the view that referrals were necessary part of the GPs role:

**Sixth Form males focus group 1**

*L : Maybe they feel that having a conversation with a specialist will be better for you because they actually know what they're doing actually really good at that rather than sitting there and.*

*G: Blagging their way through it.*

*L: Yeah and they're qualified for the more physical side.*

One participant in the Asian female focus group disagreed with the group and stated that she felt that GPs could in fact be confidential. This view was supported by Interviewee 1 who noted that GPs were the only service that she could trust to be confidential. One other Asian female in the Student group also advocated that she felt comfortable with her family GP compared to speaking to someone that she did not know.

**Asian female group wave 1**

*P5: I wouldn't go and tell my GP anything because she'd go to my mum because they're good mates as well.*

*R: Really?*

*P5: Yeah.*

*(Giggling)*

*R: Anything else what do people think on this side?*

*P3: I think I would personally I've been to my GP before for not that reason but so I think I would.*

*R: Yeah.*

*P3: Plus there's no way that my mum could find out.*

*P6: But there is always that element - don't you think?*

*P3: You know that computer screen they have and they have all the dates on it I'm sure that my mum would look at it or something.*

*P6: What if they found out. Wow!*

Some participants felt that medication could play a positive role in providing help to young people (Students, Employed young people and Asian females).

**Employed focus group 1**

*P5: Yeah absolutely.*

*R: Yeah.*

*P5: It's not the only answer but I'd probably wouldn't be here all in one piece if it wasn't for you know I'd probably still just be around but I don't know in what sort of state I'd be in.*

*R: Do you agree with that yeah.*

*P1: Yeah I think medication has its place.*

*P2: Yeah.*

*P1: It has its place.*

Three groups agreed that counselling was beneficial (Black males, Employed young people, Sixth form females groups) as did a minority of participants in the remaining four groups and one interviewee (Interview 2). Black male participants in the Hostel group also advocated the use of counsellors as a way of supporting someone who may be depressed because they are out of work. Some participants in two groups felt that counselling would be more appropriate than a GP for mental health problems (Hostel and Sixth Form male group). The theme 'counselling is beneficial' was often developed through disagreements between participants. For example, one participant in the Hostel group suggested that counselling could be beneficial in response to the view that health services could not help:

**Hostel focus group 1**

*P4: The reason why I would not is because I don't like I don't believe that anyone could do anything for me.*

*P8: Yeah*

*P4: I would be if I told them my problems I'm thinking now hold on I'm telling them my problems but what can they really do? What can I don't just believe that they can do anything.*

*P8: They can only deal with why the problems have occurred.*

*P4: Yeah*

*P8: But the problem is within you. It is that that you have to ask yourself.*

*R: Do people agree with that?*

*P3: Yeah.*

*R: You agree with that Whitney yeah that they can't help you?*

*P3: Well mostly.*

*R: Hang on a second.*

*P7: The GPs no really but there are counsellors that can.*

*P8: That's what I'm saying if.*

*R: Finish what you're saying.*

*P7: Yeah they I mean they can advise you I mean teach you ways how to you know how you how to do say it look inside yourself and see what's wrong, what's causing the problem.*

### **Organisational theme - Importance of approachability**

Three groups agreed that it was important to feel comfortable with a health professional when seeking help for a mental health problem (Asian females, Black males and Sixth form males). In response to others talking about the embarrassment of seeking help one participant in the Employed group felt strongly that the decision to see a counsellor was largely affected by whether she felt the counsellor understood what she had experienced and not by how embarrassed one may be but about it:

#### **Employed Focus group 1**

*P3: I ... I couldn't see how they would help me until I started talking to them actually.*

*R: Yeah.*

*P1: She had to get comfortable.*

*P3: I had to know the person because it was like I don't know you your ok but with total strangers you can be whatever for all I know I don't know it was a matter of getting to know him and yeah they can understand my situation they most probably have had the problem but there's worse in a situation with other people.*

The concept of feeling comfortable with a health professional was also supported by a minority of participants in the remaining four groups and two interviewees (Interview 1 and 2). Within the sixth form male group, the Black participants noted the importance of having a health professional of the same race and skin colour and felt it was important to have a good relationship with a GP in order to disclose your emotions. Sixth form males also noted that they would feel more comfortable with a GP that they knew or had seen previously. Contrastingly, visiting a family GP was considered to be a barrier for some Asian females.

#### **Sixth form males focus group 1**

*P7: You're probably right say like if you don't go to the doctor often and you see your GP but if you had the same GP for like say most of your adult life say 10 or 15 years then after that*



*amount of time then maybe if you just sit down with them rather than try and refer you then they could kind of because you've got a friendship or relationship they could try and help you more than just a physical fashion.*

A minority of participants in all groups across the data set (except Sixth form females) noted that it would be useful to treat young people with similar ages and experiences. Students agreed that it was useful to access help for mental health problems alongside other services. This theme was also supported by a minority of participants in all six of the other groups:

#### **Asian females focus group 2**

*P7: I think what would help is if that this whole emotional business was actually in the actual doctor bit.*

*Group: Yeah.*

*P6: Like a counsellor there.*

*P7: Yeah so then it won't be because you are actually to the counsellor you could say you're coming to a doctors appointment and so you can yeah just quickly sneak in.*

*R: So no one see you yeah that's true actually it's a good idea yeah they do actually have a lot of GP surgeries do actually have counsellors you know in a room downstairs you know whether they have them linked in and they can refer you straight there so it's not actually you having to go a long distance so.*

#### **Organisational theme - Lay knowledge is diverse**

Participants used a variety of different terms to describe mental health problems. As well as using clinical terms such as 'self-harm' and 'schizophrenia' when asked to describe mental health problems, participants also used behavioural terms e.g. 'violence' and 'becoming withdrawn' as a indicator of a mental health problem. The word 'depression' or 'depressed' was also used to describe the character in the vignette by a majority participants in all seven focus groups and all three interviews. The vignette described core clinical symptoms of depression. This indicates that young people can correctly identify symptoms of depression. The words 'stress' 'stressed' or 'stressful' were also used by participants in all of the groups. A wide range of existing services (other than GPs) were suggested by participants as sources of help for young people with mental health problems. There was agreement among Black males that drop in centres were a good source of support:

## **Black males focus group 1**

*P2: Drop-in centres*

*R: Drop-in centres*

*P6: Connexions as well?*

*R: hang on, hang on, one sec, what were you saying?*

*P5: Guys like (name of youth worker) like*

*R: why what's so special about (name of youth worker)?*

*P5: there's nothing special about (name of youth worker) but*

*[Group laughing]*

*P5: But like if was going to go to (name of youth worker with a problem, the way he talks to me is like he's been through it even if he hasn't been through it, but he knows how to talk to people, it's not like he's just doing it, he wants to talk to you about it so that he can help you. Some people just do it because you come to them with a problem*

*P4: I didn't know about that - if I didn't know Kemi (youth worker-name has been changed) like you get me I didn't know that these places exists like ACAPS (Alcohol Counselling and Prevention Services)*

*R: How did you find out then, about this place?*

*P6: My friend told me*

*R: Your friend told you*

*P4: Someone told me about this place, talking to him isn't it? And he told me about it*

*P3: I was walking and someone said are to coming ACAPS? [Group Laughing]*

Drop-in centres were also considered useful by a minority of participants from two other groups and one interviewee (Employed and Student groups and Interview 2). Young people living in a hostel agreed that key workers were an important source of help as did one participant in the Black male groups. Some participants also noted the following as potential sources of help: Schools and Universities (Student, Interview 1); the Church (Black males, Employed); clinics (Sixth form females); the internet (Employed); Accident

and Emergency services (Employed); alternative therapies (Sixth form males, Sixth form males, Students); and phone-lines (Employed, Hostel, Sixth form males, Student, Interview 1).

### ***Help seeking as functional: group differences***

There were a number of group differences which emerged across the themes. Within the theme 'when self-reliance is not enough' the all male focus groups tended to support the basic themes 'cannot manage by yourself' and 'reaching a crisis as a point for help' and female groups endorsed the themes 'identified a need for help, and 'importance of seeking help from someone who is objective'.

Participants living in a hostel had the least support for informal sources of help. A minority of participants in the hostel group mentioned peers as a source of help. Conversely all six of the other groups agreed that it was important to confide in friends. Some participants from the same six groups, but not the Hostel group, also felt that parents were also an important source of help.

The view that GPs and counsellors were useful was endorsed by participants in the Employed focus groups across all three basic themes; positive views of GPs, counselling as constructive and medication has a role. Black males and Sixth form females agreed that counselling was constructive and had positive views of GPs. An endorsement of counselling was also put forward by the male participants with an African-Caribbean background from the Hostel and Sixth form male groups.

### **Global theme: Help seeking as risk**

Help seeking was also associated with a number of risks. This network is made up of the following three organisational themes: fear of negative consequences; lack of confidentiality; and concerns about approaching close friends and family (see figure eight below).

#### ***Organisational theme: Fear of negative consequences***

A minority of participants across four groups felt that it was embarrassing to seek help (Asian female, Black male, Student and Sixth form male groups). Two groups agreed that young people may be concerned about being judged by others (Asian females and Sixth form males). This theme was also supported by data from a minority of participants in the Student group. Sixth form females agreed that people with mental health problems can experience stigma. This theme was supported by data from a minority of participants in two

other groups and one interview (Student and Asian female group and Interview 2). The Employed group agreed that there is a stigma attached to having a diagnosis and disclosing your mental health problems in the work place:

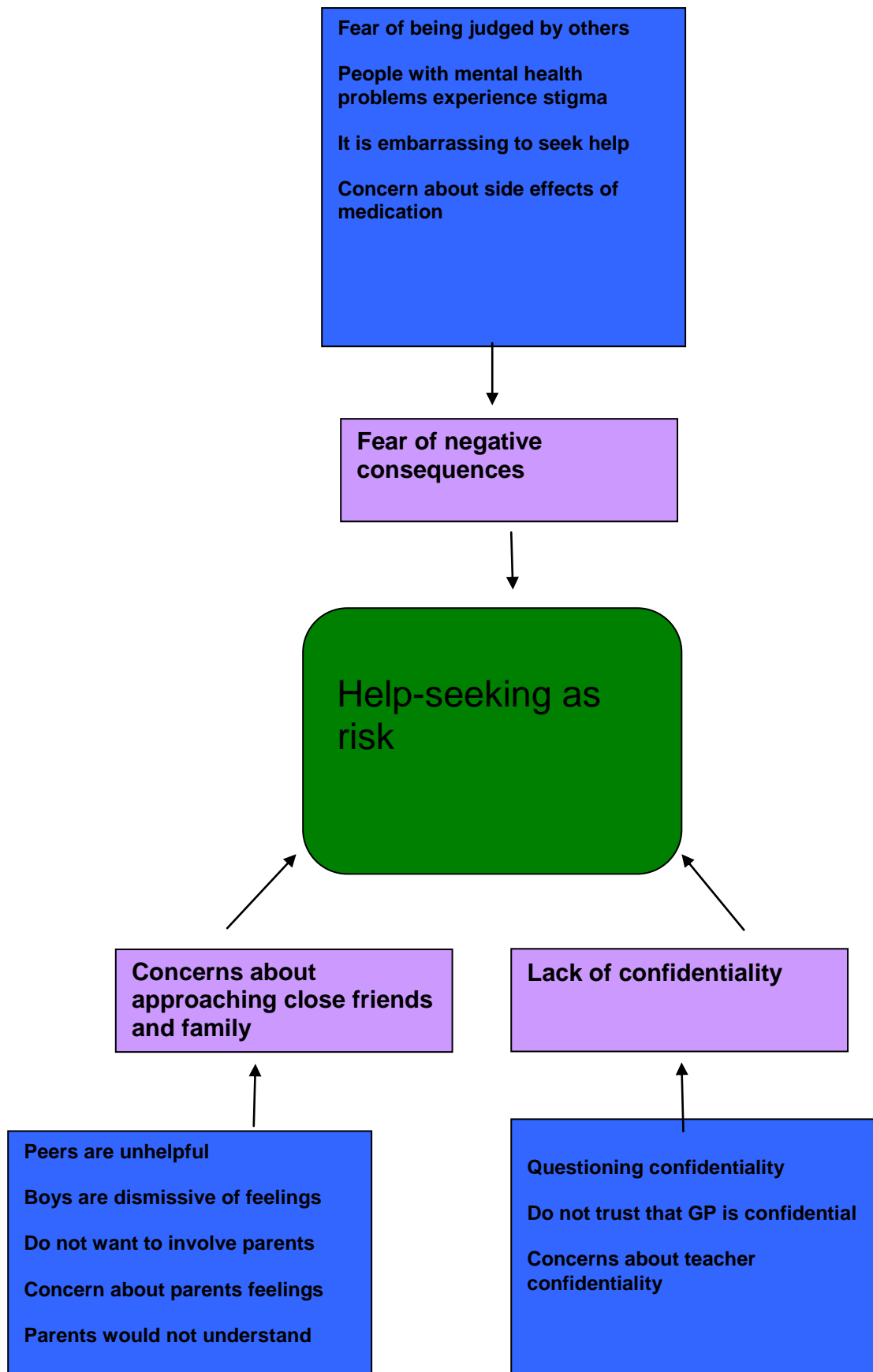
### **Employed focus group 2**

*P1: Yeah there is that stigma but it's to be really diagnosed with mental health is a stigma which is the word everywhere... not just the workplace it's just everywhere basically I mean it's just everywhere if I didn't have some sort of understanding of a person that has either schizophrenia to say you know there are people that are like there not violent don't always go out and stab someone or kill someone and you know that kind of you know that kind of knowledge at least or to have an understanding of if someone is breaking down ok I can see their breaking down or anything like that nobody really, really wants to deal with people that have mental health problems or that are on the verge of mental health problems because they tend to find that they are either in a very vulnerable position basically I mean skim around it really so its become vulnerable people you know more sort of they don't want to deal with them basically.*

*P5: That's right.*

*P1: I think really because they just don't know how to deal with them.*

Figure eight: thematic network 6 - Help seeking as risk



Asian females agreed that they would be concerned about the side effects of medication. Some participants felt that medication should be a last resort and not so readily available (Interviewee 1, Students, and Sixth form males). It is interesting to note that issues raised about medication came from a majority of participants that had not disclosed taking medication. Those with experience felt that medication had a role.

**Asian Females focus group 1**

*P7: I think taking medication I think it just makes you dependent on that medication as well as I think it makes you think that your more ill than you actually are because like when I don't know like you know when like you're getting a cold and you try to ignore the symptoms and like everyone's like it'll go away or whatever and then maybe I think your thinking to yourself that your ill and so you are ill and then you I think you act it a little bit.*

**Organisational theme: Lack of confidentiality**

Some young people questioned confidentiality. Three groups agreed that they would be concerned about GP confidentiality (Sixth form females, Asian females and Sixth form males). However, it is also important to note that some Asian females thought that their GP was confidential. Young Asian women were particularly concerned about teacher/student services confidentiality. On two occasions the Student group joked about seeking help from someone through student support services who they could then have met socially or in another capacity on campus.

**Asian Females focus group 1**

*P8: I've never been to a GP in my life about problems like that I've only been with my mother and that was like because I had a cold apart from that I've never been to my GP and I would never go to one personally I wouldn't have the bother because he is Indian and he would tell my mum.*

### **Organisational theme: Concerns about approaching close friends and family**

This theme shows that whilst peers and parents were considered important sources of help (as shown earlier), relationships with peers and parents were also considered to be problematic. Sixth form females agreed that friends would not be helpful. A minority of participants from four groups felt that peers may be unhelpful by acting immaturely, not being interested or not respecting confidentiality (Asian females, Hostel, Sixth form males and Employed).

#### **Sixth form Females focus group 1**

*P7: It's easier for someone that knows you to judge you really quickly as if it was someone that you didn't know they wouldn't be so judgmental.*

*P5: And I suppose whatever they could say you could take it as a maybe easier say it was like your friend who judged you then you'd maybe feel a bit conscience like telling them other stuff because of what they've said or whatever.*

*[Group – nodding] - Yeah.*

*R: Go on what else is there anything else?*

*P3: The thing like you can also like get advice that's not that doesn't seem like too... like your friends will give you advice that won't be real so they'll slap it up make it something that it's not.*

*P4: They'll give you what you think.*

*P5: What you want to hear yeah.*

*Yeah.*

*R: And it's not always positive it's not always best advice?*

*P3: Yeah but it's what you're going to hear.*

*P1: I think in some emotional health problems are worse than like any other sort.*

*P3: Definitely.*

*P1: Because it's so hard to help yourself with that kind of thing.*

*P6: Also if it is emotional if you tell your friends they might start acting differently towards you which makes it even worse. Or they may act really delicate towards you...*

Some Asian females felt that young people seek help in order to get attention from their peers. This perspective was put forward by two of the dominant group members which may have silenced others from challenging their views. A minority of participants in the two all male groups felt that seeking help from other male peers was often unhelpful because they were dismissive of feelings (Sixth form male and Black males):

**Sixth form males focus group 1**

*P7: It's a start. Talk to friends first*

*P5: Talk to a girl.*

*P1: Standard*

*P5: No seriously because girls understand so much more than boys.*

*P1: For real*

*P5: You can't chat to a boy but if it is a girl you can chat to her about anything.*

*R: What do people think about that?*

*P1: It's true.*

*P7: It's true.*

*P5: Because boys just don't understand*

*R: Yeah.*

*P1: Boys are just mental boys just think mental you get me? They will just sit there and think you're idiot man why are you thinking like that for? Chill out man! You get me?*

*P5: It's like there is not problem!*

*R: Yeah ok so if he talks to a girl a friend or a girlfriend or whoever.*

*P1: Girls are more likely to sit down and be like ohhhh!!*

*P5: Boys don't show that*



A minority of participants in two groups were aware that others might be upset to know that a member of their family or close friend is experiencing problems (Sixth form males and Employed young people):

**Sixth form males focus group 1**

*The person you know well could like worry and then you're worrying because they are worrying and it just all goes downhill from there.*

The previous thematic network illustrated that personal relationships are an important first source of help for young people (see figure seven above). However, Asian females agreed that parents would not understand if their child sought help for a mental health problem. This was also expressed by all three interviewees. The Asian females began to giggle during this moment in the focus group which indicates that disclosing to parents was a sensitive area of discussion. Concern that parents would not understand that their child had sought help was also supported by some participants in the Black male group.

**Asian Females focus group 1**

*P7: I think from the very beginning.*

*[Group giggling]*

*P7: From the very beginning I think your parents like put it into you that you know like something's you're not meant to talk about.*

*Group: Yeah.*

*P7: Right and like the whole I don't know if this is relating to anyone else but the whole Asian thing about how they're quite over-protective about you you've got to be quite not shy but you've got to keep things quite close to yourself you can reveal yourself too much and like I don't know cant.*

*R: Yeah do people agree with that what do you lot think on this side?*

*P4: Yeah so you cant really view your opinions you've got to just kind of go along what other people are saying don't make yourself stand out.*

*P7: Yeah.*

*P4: Sort of thing.*

*P7: You've got to like fade into the background you've got to fit in.*

A minority of participants in two groups did not want to involve their parents (Hostel group and Sixth form males):

#### **Hostel group focus group 1**

*P4: Not all people want to go and talk to their parents about their business.*

*P3: True, true.*

*P4: And not all people want to.*

*P3: Because then you have already left your house isn't it so its like its your life you're moving on with your life you want to how you see best fit because you've been living in the house and you feel the way they want you to run your things is not how you think is best so if you want to do your things your way you don't its like pride what I said about pride in the first place you don't want to go back to your parents and start saying I've got these problems because then.*

*P5: Yeah once you've already left.*

Sixth form females agreed that parents often have high expectations of their children. This impacted upon whether they would feel comfortable telling them about a mental health problem. This theme was supported by data from some participants in the Asian female group and all three interviews.

#### **Sixth form females focus group 1**

*P2: Sometimes it's the fact that they are your parents that you can't talk to them.*

*R: Well that's yeah.*

*P2: About certain things.*

*R: Yeah.*

*P2: So that you can talk to them about anything but it's just sometimes because they are your parents you can't talk to them about everything.*

*R: Yeah.*

*P2: Like if I told my mum she'd hit the roof and then she'd go mad at me and try and change my mind and stuff like that.*

### ***Help seeking as risk: Group differences***

The following group differences emerged from the analysis. Participants from focus groups with younger participants (16-17 year olds) agreed that young people seeking help may experience stigma from others and also were agreed in their concern about GP confidentiality. Issues about confidentiality seemed to be marked for Asian females. In addition to their concern about GP confidentiality, Asian females were hesitant to seek help from teachers as it was felt that they may not be confidential. Asian females in the other groups were also particularly concerned about confidentiality. Within the theme 'concerns about approaching close friends and family', participants in the female groups endorsed the view that parents would not understand why their children had sought help. In addition, participants in the female groups also felt that parents have high expectations of their children which would stop them from discussing their difficulties with their parents. The all male groups and male participants within mixed gender groups felt that their male friends would be dismissive of their feelings if they approached them for help.

## **Development of the quality indicators**

The quality indicators were developed from an initial thematic analysis of the focus groups and interviews with young people, participatory research groups and nominal groups with young people.

## **Initial thematic analysis of the focus group data**

Thematic analysis of the focus group and interview data resulted in the following coding framework illustrated in Table 17. Codes highlighted in bold were chosen to develop the quality indicators.

**Table 19: Initial coding frame**

General code	Sub-code	General code	Sub-code
<b>Confidentiality</b> <b>Recording information</b>		Reasons for not seeking help	Awareness of a problem <b>Awareness of services avail</b> <b>Negative response</b> Difficulty talking to someone Wanting to handle it yourself
<b>Counselling</b>	<b>Being informed</b> <b>Group therapy</b> <b>Negative</b> <b>Neutral</b> <b>Pathways</b> <b>Positive</b> <b>Professionalism</b> <b>Student counselling</b>	Reasons for seeking help	Advised to go For information/reassurance <b>Needs of someone experiencing</b> Response to a crisis
<b>Features of an ideal service</b>	<b>Access</b> <b>Client Group</b> <b>Clinics/Drop in centres</b> <b>Information centres</b> <b>Existing services</b> <b>Staff and Skills</b>	<b>Other places/persons for help</b>	<b>Accident and Emergency</b> <b>Church</b> <b>Clinics</b> <b>Drop in centres</b> <b>Homeopathy/Alternative</b> <b>Phone lines</b> <b>School</b>
<b>Gender differences</b>		Relating	Similar experiences Talking to mates/sibs/cousins <b>Talking to a health professional</b>
<b>GP</b>	<b>Accessibility</b> <b>Confidentiality</b> <b>Language and interaction</b> <b>Negative</b> <b>Neutral</b> <b>Nurses</b> <b>Physical vs. Mental health</b> <b>Positive</b> <b>Recognition/Training</b> <b>Referrals</b>	<b>Self-help</b>	
Manifestations of a MH Problem	Alcohol/Drug Use Descriptions/Diagnosis	<b>Stigma</b>	
		Stress or mental health problem?	
		Teachers/School	
		Work place	
<b>Medication</b>	<b>Negative</b> <b>Neutral</b> <b>Positive</b>		

## **Results of the participatory research groups**

The participatory research groups yielded a total of forty-nine quality indicators from the focus group data (detailed below in table 20). The quality indicators represent the following four areas of primary care. Quality indicators 1-9 refer to issues of practice organisation and include advertising the availability of primary care to help young people, providing information and primary care practitioner (PCP) skills. Quality indicators 10-21 are about treatment options and cover antecedents to prescribing medication and referral protocols. Quality indicators 22-34 refer specifically to the consultation process, and include putting young people at ease, confidentiality and suggestions for improving interaction with young people. Quality indicators 35-49 illustrate features of an ideal service such as improving accessibility and environmental preferences of a primary care practice. See table 20.

## **Results of the pilot nominal group**

As a result of piloting the 49 quality indicators with young service users, amendments were made to 25 quality indicators (detailed in table 21). The following quality indicators were removed due to duplication:

- Quality indicator 10  
Primary care practitioners should explain treatment options to young people
- Quality indicator 12  
Primary care practitioners should spend more time talking to young people before prescribing to make sure that medication is the right treatment for them.
- Quality indicator 40  
An ideal service would be inside the primary care service

The amendments resulted in quality indicators that were more succinct, better aligned to the terms used by young service users, and with an appropriate emphasis as dictated by the young service users. This process resulted in 46 quality indicators to be presented to the final nominal group. The amended quality indicators are detailed in table 19 below.

**Table 20: Quality indicators developed by the participatory research group**

**Quality indicators 1-9: The Practice**

Quality indicator 1: Primary care practitioners should advertise that they are available to help young people with mental health difficulties.

Quality indicator 2: Primary care practitioners should advertise the availability of longer appointments for young people.

Quality indicator 3: Primary care services should have mental health specialists for young people to reduce the stigma of attending mental health services.

Quality indicator 4: Primary care practitioners must have up-to-date information about other local services to give to young people.

Quality indicator 5: Primary care practitioners should have up-to-date information about local specialist mental health services.

Quality indicator 6: All primary care practitioners should have mental health training.

Quality indicator 7: Primary care practitioners should have basic counselling skills to provide young people with immediate help whilst waiting for specialist mental health services.

Quality indicator 8: Primary care practitioners need to be aware that physical symptoms can occur alongside and/or be an indication of emotional distress.

Quality indicator 9: Primary care practitioners need to be aware that once a young person has built up the confidence to see them about a mental health problem they need help and they need it immediately.

**Quality indicators 10-21: Treatment options**

Quality indicator 10: Primary care practitioners should explain treatment options to young people. (removed)

Quality indicator 11: Primary care practitioners should discuss other treatment options before prescribing medication to a young person.

Quality indicator 12 Primary care practitioners should spend more time talking to young people before prescribing to make sure that medication is the right treatment for them.

Quality indicator 13: Access to talking therapies needs to be made easier as an alternative to medication for mental health problems.

Quality indicator 14: Primary care practitioners should explain to young people that medication is not a solution to their mental health problems but can be one of the first steps to solving them.

Quality indicator 15: Primary care practitioners should be aware that for some young people taking medication could make them think that they are seriously ill. Therefore they need to provide reassurance that medication is a short-term solution and can make them feel better.

Quality indicator 16: Referral times for young people should be as short as possible to reduce the stress experienced while waiting for an appointment.

**Quality indicator 17: If making a referral primary care practitioners should provide information for young people about what to expect at the first appointment.**

**Table 20: Quality indicators developed by the participatory research group (continued)**

*Quality indicator 18: For referrals outside the GP surgery, directions on how to get there should be provided by primary care practitioners.*

Quality indicator 19: For referrals within the GP surgery, primary care practitioners should keep the young person up to date with the progress of the appointment.

Quality indicator 20: For referrals that are to the practice counsellor, primary care practitioners should attend the first appointment to introduce the young person to their counsellor.

Quality indicator 21: Primary care practitioners should advise young people seeking help through counselling that it may take some time until they feel the benefits to their mental health.

**Quality indicators 22-35: The consultation**

Quality indicator 22: Counsellors need to be more interactive with young people rather than just listen and write notes.

Quality indicator 23: Primary care practitioners should discuss self-help strategies together with other treatments offered.

Quality indicator 24: Primary care practitioners must reassure young people that they will not be judged negatively for seeking help for an emotional or mental health problem.

Quality indicator 25: Primary care practitioners need to reassure young people that they have the training and expertise to help them with their problems

Quality indicator 26: Primary care practitioners should appreciate that young people can feel stupid, embarrassed and ashamed to seek help for mental health problems.

Quality indicator 27: Primary care practitioners must understand that being diagnosed with a mental health problem is stigmatising.

Quality indicator 28: Primary care practitioners should have a strict confidentiality policy, which they state, at the beginning of the consultation preventing them from disclosing information to members of the young person's family.

Quality indicator 29: Primary care practitioners should attempt to ask more questions and develop a rapport with a young person during consultation.

Quality indicator 30: Primary care practitioners should ask questions about a young persons' support network/ relationships before making a treatment decision.

Quality indicator 31: Primary care practitioners should accept information about a young person's problem in writing rather than face-to-face.

Quality indicator 32: Young people should be encouraged to take a confidant into consultation to support them.

**Quality indicator 33: Primary care practitioners need to be aware that young women are more open about discussing their emotions than young men.**



**Table 20: Quality indicators developed by the participatory research group (continued)**

<p><i>Quality indicator 34: Primary care practitioners need to be aware that young men find it difficult to admit that they have an emotional problem and can often express their feelings in an aggressive way.</i></p> <p>Quality indicator 35: Primary care practitioners should be aware that seeking help for a mental health problem can affect a young person's image of themselves.</p> <p>Quality indicator 36: Primary care professionals must be aware that young people prefer younger practitioners.</p> <p><b>Quality indicators 37-49: Features of an ideal service</b></p> <p>Quality indicator 37: An ideal service should be in a location others will not be able to know that you are there for mental health problems.</p> <p>Quality indicator 38: The name of an ideal service should be something discreet such as the 'information centre' and not 'the mental health clinic'.</p> <p>Quality indicator 39: An ideal service should be easily accessible from a number of places such as schools and colleges.</p> <p>Quality indicator 40: An ideal service would be inside the primary care service. (removed)</p> <p>Quality indicator 41: An ideal service should have alternative ways of giving advice and support such as phone lines and email addresses to contact.</p> <p>Quality indicator 42: An ideal place for help with mental health problems would be accessible to young people out of working hours.</p> <p>Quality indicator 43: An ideal service would be accessible without having to make an appointment.</p> <p>Quality indicator 44: An ideal place for help with mental health problems would be in an informal environment.</p> <p>Quality indicator 45: An ideal place for help with mental health problems would offer a variety of treatments for young people.</p> <p>Quality indicator 46: An ideal service would have young staff.</p> <p>Quality indicator 47: An ideal service would have staff with experience of mental health problems.</p> <p>Quality indicator 48: An ideal service should be integrated into places where young people are already engaged in such as youth clubs.</p> <p><b>Quality indicator 49: An Ideal service will be for a specific age group and not all ages.</b></p>
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**Table 21: Amended quality indicators**

<p><i>Quality indicator 3: Young people should be able to see a mental health specialist at the GP surgery.</i></p> <p>Quality indicator 10: Primary care practitioners should explain treatment options to young people. (removed)</p> <p>Quality indicator 12: Primary care practitioners should spend more time talking to young people before prescribing to make sure that medication is the right treatment for them. (removed)</p> <p>Quality indicator 20: When referring to a counsellor within the GP surgery, primary care practitioners should attend the first appointment to introduce the young person to their counsellor.</p> <p>Quality indicator 21: Primary care practitioners should advise young people seeking help through counselling that it may take some time until they start to feel better.</p> <p>Quality indicator 23: Primary care practitioners should discuss ways that you can help yourself overcome the symptoms of mental health problems</p> <p>Quality indicator 26: Primary care practitioners should appreciate that young people can feel embarrassed to seek help and should reassure them that mental health problems are common.</p> <p>Quality indicator 27: Primary care practitioners should understand that being told you have a mental health problem could make a young person feel like they are being 'labelled'</p> <p>Quality indicator 30: Primary care practitioners should ask questions about young persons' relationships and support network.</p> <p>Quality indicator 31: Young people should have the option of bringing information that they have written about their symptoms and feelings for the primary care practitioner to read.</p> <p>Quality indicator 33: Primary care practitioners should be aware that young women could often be more open about discussing their emotions than young men.</p> <p>Quality indicator 34: Primary care practitioners need to be aware that young men can find it difficult to admit that they have a mental health problem and can often express their feelings in an aggressive way.</p> <p>Quality indicator 35: Primary care practitioners must be aware that seeking help for a mental health problem can affect a young person's image of themselves</p> <p>Quality indicator 36: Primary care professionals must be aware that young people might prefer to disclose personal information to someone of similar age and gender.</p> <p>Quality indicator 37: An ideal place for help with mental health problems should be located within the GP surgery so that people will not know what you are there for.</p> <p>Quality indicator 38</p> <p>: An ideal place for help with mental health problems should have a discreet name such as the 'information centre' and not 'the mental health clinic'.</p> <p><b>Quality indicator 39: An ideal service for help with mental health problems should be easily accessible from a number of places such as schools and colleges.</b></p>
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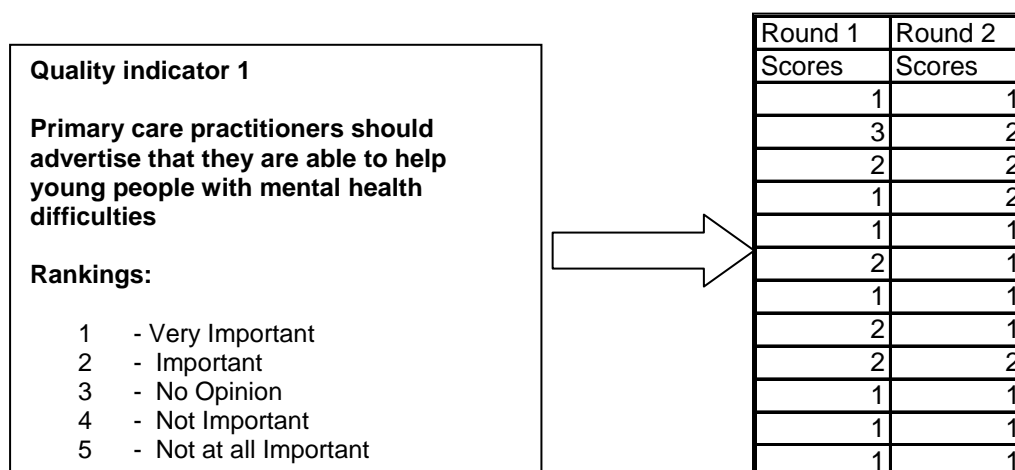
**Table 21: Amended indicators (continued)**

<p><i>Quality indicator 40: An ideal service would be inside the primary care service (removed)</i></p> <p>Quality indicator 41: An ideal service should offer young people the option of phone-lines and email to get support for mental health problems as well as seeing them face to face.</p> <p>Quality indicator 42: An ideal place for help with mental health problems should be accessible to young people out of working hours.</p> <p>Quality indicator 43: An ideal place for help with mental health problems should be accessible without having to make an appointment.</p> <p>Quality indicator 45: An ideal place for help with mental health problems should have young staff.</p> <p>.Quality indicator 47: An ideal service will have staff that have had mental health problems themselves.</p> <p>Quality indicator 48: An ideal service for help with mental health problems should be available at places where young people already go e.g. at college or youth clubs</p> <p><b>Quality indicator 49: An ideal place for help with mental health problems would be for 16-25 year olds only.</b></p>
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## Results of the nominal group: the quality indicators and corresponding methods of assessment

The individual ranking and median scores for each quality indicator are shown in appendix 4 however an example of the results is provided in figure 9 below. The scores of the 12 youth expert panel YEP members converged between rounds 1 and 2 as illustrated below (Murphy, et al 1998). Sixteen quality indicators met the criteria for agreement (see table 22). These relate to issues both at the level of the primary care practice and the actual consultation process. Advertising the ability to seek help, when suffering from mental health problems, from a PCP, training in mental health for PCPs and the availability of a mental health specialist at the surgery were all considered important quality indicators for a good primary care service. Other quality indicators included providing young service users with information about local services, explaining the referral process, and increasing a young person's access to talking therapies at the surgery. Young service users decided that PCPs should explore alternative options before prescribing medication, should discuss methods of self-help, should ask about social support available to the service user, and should employ a policy of confidentiality and empathy during every consultation with a young person. Finally, the provision of a variety of treatments was considered the most important part of an ideal primary care service for young people experiencing mental health problems.

**Figure 9: Quality indicator 1 with individual rankings for round 1 and 2 YEP**



Effective ways of assessing whether a quality indicator was in place are also detailed in table 11. These can be classified into the following four categories.

1. Checking for items in place in the practice was considered to be an efficient way to monitor the availability of posters and leaflets advertising the information called for in the quality indicators (e.g. mental health services in the surgery and the local area for young people).
2. An assessment of a PCPs attendance on mental health training courses and a checklist of their mental health qualifications was put forward as a way of monitoring the skill base in relation to mental health problems in young people.
3. Being given information about what to expect at a first appointment after being referred to a mental health service, keeping a young person up to date with the progress of their appointment, and stating the confidentiality policy were best monitored by a survey of patient experience after consultation with a PCP.
4. Finally a “mystery patient” reporting on their experience was considered the most unbiased method of assessment.

The quality indicators were presented to primary care professionals through a series of focus groups and interviews. The results will be presented in the next section.

**Table 22: Final quality indicators and methods of assessment**

<b>Quality indicator</b>	<b>Method of assessment</b>	<b>Quality indicator</b>	<b>Method of assessment</b>
1) Primary care practitioners should advertise that they are available to help young people with mental health difficulties.	Check to see if there is a poster in waiting room	2) All primary care practitioners should have mental health training.	1) Check staff records of mental health training courses attended/qualifications obtained
3) Primary care practitioners should have up-to-date information about local specialist mental health services.	1) Check if liaison-worker is in place or regular visits from mental health specialists 2) Leaflets	4) Primary care practitioners must have up-to-date information about other local services to give to young people.	1) Check for designated place and person (written into job specification) to give information about local services 2) Leaflets in the practice 3) Mystery patient
5) Primary care practitioners should discuss other treatment options before prescribing medication to a young person.	1) Checklist designed by PCPs to reflect all types of treatments available at practice signed by patient and doctor to say they have been discussed and kept in notes	6) Young people should be able to see a mental health specialist at the GP surgery.	1) Poster advertising 2) Survey patients attending the surgery 3) Check for staff qualifications and level of mental health training
7) Access to talking therapies needs to be made easier as an alternative to medication for mental health problems.	1) Check waiting lists over time to see if there has been a reduction 2) Check number of staff skilled in talking therapies 3) Check referral records 4) Check for alternative sources of talking therapies offered/ are they advertised in the practice?	8) Referral times for young people should be as short as possible to reduce the stress experienced while waiting for an appointment.	1) Time assessment linked to severity of symptoms for each patient 2) Make PCPs aware of existing guidelines for referral times

**Table 22: Final quality indicators and methods of assessment (continued)**

Quality indicator	Method of assessment	Quality indicator	Method of assessment
9) For referrals within the GP surgery, primary care practitioners should keep the young person up to date with the progress of the appointment.	<ol style="list-style-type: none"> <li>1) Monitor contact with patient i.e. referral letters and all contact with patient</li> <li>2) Patient survey</li> <li>3) Appoint a person to maintain contact with young patients</li> </ol>	10) If making a referral, primary care practitioners should provide information for young people about what to expect at the first appointment.	<ol style="list-style-type: none"> <li>1) Information provided with leaflets</li> <li>2) Patient survey after consultation</li> <li>3) Mystery patient</li> </ol>
11) Primary care practitioners should discuss ways that you can help yourself overcome the symptoms of mental health problems	<ol style="list-style-type: none"> <li>1) Leaflets</li> <li>2) CD-ROM</li> <li>3) Patient survey</li> <li>4) Mystery patient</li> </ol>	12) Counsellors need to be more interactive with young people rather than just listen and write notes.	<ol style="list-style-type: none"> <li>1) Interview patients</li> <li>2) Independent monitor during consultation</li> <li>3) Mystery patient</li> <li>4) Mock-session on videotape as part of training</li> </ol>
13) Primary care practitioners should have a strict confidentiality policy, which they state, at the beginning of the consultation preventing them from disclosing information to members of the young person's family.	<ol style="list-style-type: none"> <li>1) Poster in waiting room</li> <li>2) Patient survey afterwards</li> <li>3) Recorded in patient notes</li> </ol>	14) Primary care practitioners should appreciate that young people can feel embarrassed to seek help and should reassure them that mental health problems are common	<ol style="list-style-type: none"> <li>1) Anti-stigma leaflets and posters</li> <li>2) Checklist – was this part of their training?</li> <li>3) Patient survey – did they explain 'you are not alone'?</li> </ol>
15) Primary care practitioners should ask questions about young persons' relationships and support network.	<ol style="list-style-type: none"> <li>1) Mystery patient</li> <li>2) Patient survey</li> </ol>	16) An ideal place for help with mental health problems would offer a variety of treatments for young people.	<ol style="list-style-type: none"> <li>1) Assessment of staff qualifications</li> <li>2) Patient and practitioner survey</li> <li>3) Leaflets/posters/brochures</li> <li>4) Survey of patient records for changed treatment</li> <li>5) Mystery patient</li> </ol>

## **Primary care professionals' view of the quality indicators**

Four focus groups and three interviews were held with primary care professionals. I will present a short description of the participants that took part in each focus group and interview. Table 23 and 24 show participant details.

### *The focus group participants*

#### Focus group 1

All participants worked at the practice. The group comprised a GP, a counsellor, a psychologist, a graduate primary care mental health worker (PCMHW), a youth worker and a child mental health specialist. One was male and the other five were female. Their ages ranged from 23-60 (not all participants provided their age).

#### Focus group 2

Six of the eight participants worked at the practice. Two participants that were not based at the practice but who had expressed an interest in taking part in a focus group were also invited to attend. One of the invited participants was a retired GP who had been invited to the group because of his role in delivering mental health training to PCPs. The following participants were present: three GPs (one of which is now a trainer/clinical advisor); a clinical psychologist; a counsellor; a practice nurse; a practice manager and an educational link worker. Three were male and five female, aged 29-44.

#### Focus group 3

All three participants were GPs at the practice where the focus group was held. Two were female and one male. Ages ranged from 35-50 years old. Seven GPs were invited but only three were able to take part.

#### Focus group 4

All seven participants worked at the practice and regularly attended mental health team meetings arranged by the community psychiatric nurse (CPN). The following were present: four GPs; a psychologist; a community psychiatric nurse (CPN) and a patient services manager (PSM). Three were male and four were female ranging from 38-50 years old.



**Table 23: PCP focus group participant details**

Focus Group	Participant number	Gender	Age	Practitioner Type	Special interest	Years Practiced	Mental health training courses attended within the last 12 months
Focus group 1	1	Female	58	Psychologist (Psychol)	Psychotherapy – short term solution focussed family, couple and group	34	None
	2	Female		Counsellor (C)	Young people up to 25 yrs old	4	None
	3	Female	60	Practice counsellor (PC)	N/a	20	1) Supervision training 2) Self-harm 3) CBT 4) Psychosomatic presentations
	4	Female	23	Primary care mental health worker (PCMHW)	N/a	18 months	Post grad in PCMH
	5	Male	51	GP (GP)	Mental health in primary care	27	None
	6	Female		Child Mental health Specialist (CMHS)	Children and young people	20	Art therapy
Focus group 2	1	Female	43	GP	N/a	20	None
	2	Male	40	GP	Primary Care Mental Health	18	PCT lunchtime sessions
	3	Male	45	Clinical Advisor (CA)	Clinical governance and mental health	20	None
	4	Female	37	Teacher (school liaison worker)	Mental health education	10	Mental Health Awareness by Mental Health Trust
	5	Female	42	Practice Manager	Patient care	2	None
	6	Male	44	Counsellor	Service development	18	Clinical supervision (1 yr)
	7	Female	29	Clinical Psychologist	Children/adolescents and families	2	Family therapy CPD training
	8	Female	36	Practice Nurse (PN)	Mental health/family planning/Asthma/Travel	5 years	None

**Table 23: PCP focus group participant details (continued)**

Focus group 3	3	Female	49	GP	N/a	20	None
	1	Male	50	GP	N/a	21	None
	2	Female	35	GP	Family planning/sexual health	Less than a year	None
Focus group 4	1	Female	39	GP	N/a	7	None
	2	Female	38	Patient service manager (PSM)	N/a	N/a	Na
	3	Male	50	GP	Respiratory	20	None
	4	Male	42	CPN	Mental disorders in primary care	20	
	5	Female		Psychologist	Adults primary care 18-65	3	An oxford diploma in CT
	6	Male	47	GP	Ear Nose and Throat problems	Over 20 years	Management of depression
	7	Female	39	GP	General medicine	15	None

### *The Interviewees*

GP1 was a 56-year-old male who had practiced for 21 years. GP 1 had a special interest in mental health and health inequalities. He had undertaken training on implementation of NICE guidelines on depression and substance misuse within the last 12 months.

GP2 was a 52-year-old female who had been in practice for 18 years. She had a special interest in diabetes and coronary heart disease. Within the last 12 months she had been on a training course on depression.

GP 3 was a 47-year-old female who had practiced for 20 years. She had a special interest in GP training and mental health. She had had training on systemic therapy and teenage suicide risk assessment at the Royal College of General practitioners within the last 12 months.

**Table 24: PCP Interviewee details**

<b>GP</b>	<b>Gender</b>	<b>Age</b>	<b>Special interest</b>	<b>Years Practiced</b>	<b>Recent Mental Health Training Courses attended</b>
GP 1	Male	56	Mental health /reducing health inequalities	21	Substance misuse/substitute prescribing/ Implementation of NICE guidelines on depression
GP 2	Female	52	Diabetes/CHD	18	Depression
GP 3	Female	47	GP training and mental health	20	Suicide teenagers at RCGP/ Systemic therapy

## **Results of the thematic analysis**

A thematic analysis was conducted with the data from the focus groups and interviews using thematic networks. Each network will be used as a tool to explain the data below. The basic themes will be presented in the following format:

- Group agreement - a majority or all the participants agreed with each other
- Some participants – will be used to describe where a minority of participants agreed with each other. If there was a disagreement or alternative viewpoint offered by another member of the group this will be presented. If this is not reported it can be assumed that other members of the group did not voice an opinion or moved onto another topic.
- Named interviewees i.e. GP2 denotes GP interview number 2

Three global themes were generated from the thematic analysis: determining the accountability of primary care, examination of skills and the importance of commissioning and incentives. The participants also suggested further ways that the quality statements could be improved such as changing the terminology, adding provisos, including resources for practices, and involving other professionals. As there was approximately three times less data compared to the young people's data and hence a lower number of themes within each network, I will present the basic themes in detail and not the organisational themes as presented earlier.

### **Global theme: Determining the accountability of primary care**

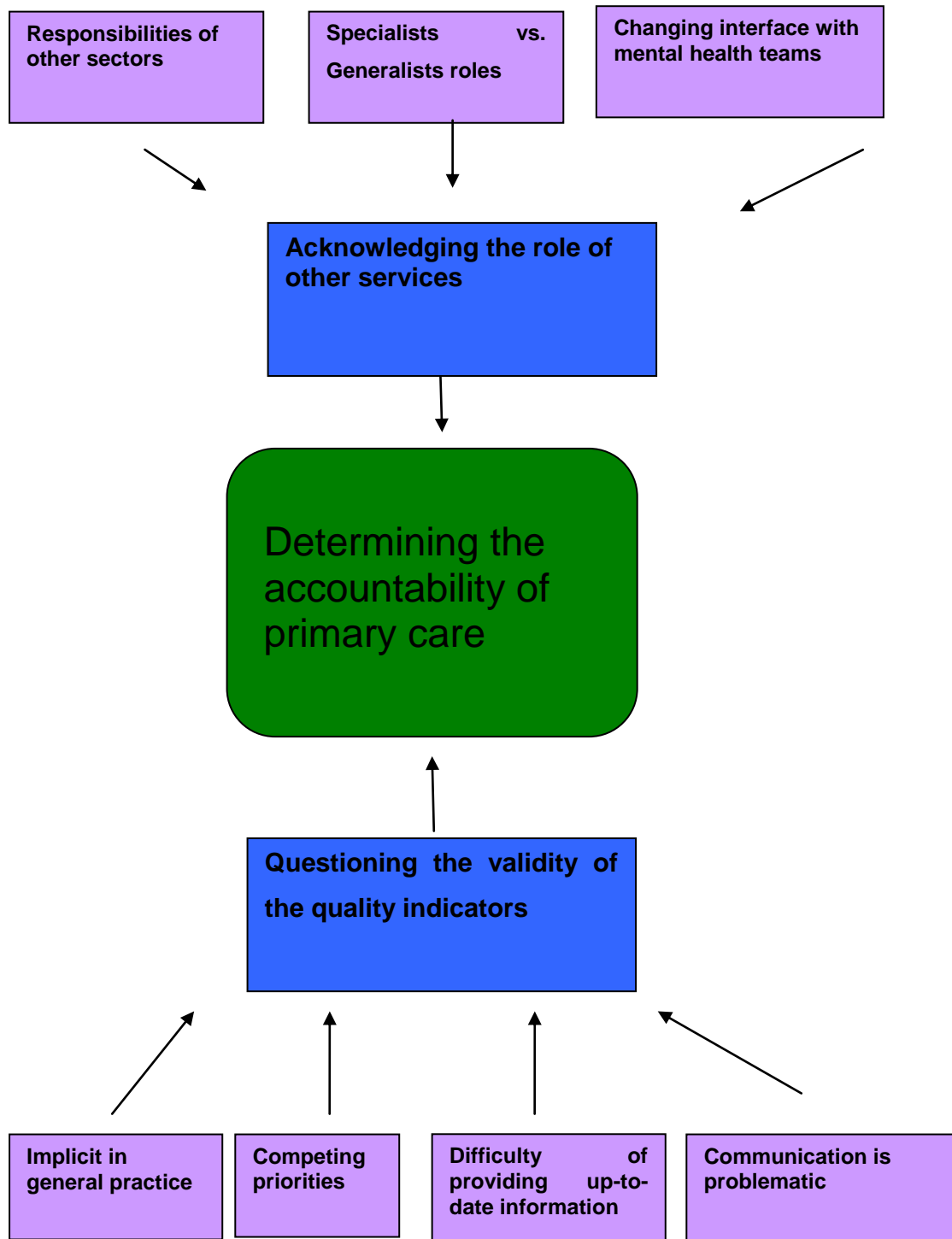
PCPs debated the responsibility of primary care regarding youth mental health problems. This thematic network is made up of the following organising themes: 'acknowledging the role of other services' and 'questioning the validity of the quality indicators'. This is illustrated in figure 10 below.

#### ***Organising theme: acknowledging the role of other services***

Many of the discussions focussed on determining which service or practitioner was best appropriate for managing young people's mental health problems. This finding contributed to the development of the following basic themes: responsibilities of other sectors,

changing interface with mental health teams and specialists versus generalists roles.

Figure 10: thematic network 1- determining the accountability of primary care



### ***Basic theme: responsibilities of other sectors***

Focus group 1 agreed that Primary Care should not be considered the only place to get help. These participants believed that schools and colleges provide access to Counselling services and referrals to Child and Adolescent Mental Health services (CAMHs) reducing the need to seek this help through primary care. This view was also put forward by some of the participants in focus group two and two GP interviewees. GP3 felt that other agencies such as youth workers also had a remit to look after young people's mental health. A community practice nurse (CPN) in focus group 4 felt strongly that the education sector was an importance source of help for young people with mental health problems:

#### **Focus Group 4**

*P4 (CPN): ...individuals who are still at school or at college can actually get health care and counselling without actually coming to primary care for it. There are facilities set up at school level and at college level. I know this both through knowing about services but also having seen people and asked about their histories and found out that they've had counselling or been referred for support without ever going to coming to primary care for it. So there's a few possible reasons why we see, I don't get that many referrals of people who are under 18 or certainly under 16 a few but not that many.*

The CPN in focus group 4 also asserted that it was important for young people to be offered a non-medical solution before coming to primary care. GPs felt that many depressed young people required social support more than medical help (FG3-1, GP1, GP3):

#### **Focus group 3**

*P3(GP): yes but we don't want to encourage people to medicalise their social problems while at the same time we do want to make sure we pick up the very real mental health problems*

GPs acknowledged that other agencies should keep PCPs up to date on what they can offer young people. One GP participant in particular felt that the responsibility for keeping a young person up to date with a referral lay with the agency to which the person is being referred to (Focus group 1).

### ***Basic theme: specialist vs. generalist roles***

GPs drew a distinction between generalist and specialist roles for dealing with serious and enduring mental health problems. The GP focus group agreed that they would refer young

people with problems involving substance abuse and psychosis to a specialist. This view was also supported by a GP participant in focus group 4 and one GP interviewee.

### **Focus Group 3**

*P3 (GP): not really I think that drug and alcohol generally really is something we feel should be managed properly with a specialist agency really. It needs a specialist training.*

Participants in focus group 4 agreed that it was more appropriate for youth mental health problems to be dealt with in secondary care. Some participants also noted that PCPs may not consider counselling as part of their remit (GP 3 and GP1 and focus group 2). It was felt that GPs often refer on because they do not have the time to discuss mental health problems in the consultation. Some participants in focus group 2 felt that GPs do not have supervision to support them in their mental health work:

### **Focus group 2**

*P1 (GP): But can I also say that I think that's you know although I am a great advocate of GPs doing a lot doing a certain amount of work there is no system in place to support them doing that.*

*P2 (GP): No supervision.*

*P1: Or specialist mental health teams have you know have a supervision they have a you know a whole process whereby you know GPs.*

*P5 (PM): They have their own counsellors.*

There were divergent views on whether Primary Care should provide mental health specialists at the surgery for young people<sup>9</sup>. Some participants in focus group 1 felt that they were already meeting quality indicator 6 as they provided access to several psychologists, a graduate PCMHW and adolescent health worker. However, GP1 believed that quality indicator 6 was 'not deliverable or desirable' and relied upon referral to secondary care.

Some participants felt that providing information gave patients more options to seek help that did not necessarily involve the GP but perhaps were more appropriate to their needs such as a local counselling service (Focus groups 1, 2 and 3 and GP3):

### **Focus group 3**

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<sup>9</sup> Quality indicator 6) Young people should be able to see a mental health specialist at the GP surgery.



*P3 (GP): I do think just going back to the stuff about giving them information that we could maybe have more information than advertised in the waiting room about services for young people that don't necessarily involve coming to see the GP because there was this point about the stigma of a mental illness and probably a lot of people would prefer to go direct to a counselling organisation rather than come and talk to their GP first and I've certainly had patients come to see me who want to be referred to a counsellor because they refuse point blank to tell me what its all about because they don't want to talk to their GP about it they want to talk to the counsellor. Um so I think that advertising some service where they can go directly to a counsellor would be quite helpful.*

### **Basic theme: changing interface with mental health teams**

Two participants believed that links between Mental Health Teams and primary care were diminishing because secondary services have become increasingly concerned with serious mental health problems (the CPN in focus group 4 and GP1). It was recognised that this shift reduces the availability of referrals from primary care for common mental health problems:

#### **Focus group 4**

*P4 (CPN): in the past there was a link worker. We have had a consultant come to our meetings actually staff from LEO [Lambeth Early Onset] come here to present. I mean in the past the consultant used to come to all the meetings actually he used to come here every month so there was a very strong link and there was a designated member of staff who would be the contact. That has gone by the by actually. Part of that is because secondary services have decided to concentrate specifically on very severe what they call severe and enduring mental health problems. Their kind of remit has moved away from concerns of the many.*

GP1 felt that mental health services were not as responsive to the needs of young people since being re-structured. One participant in the GP focus group felt that the availability of primary care sessions with CAMHs specialists negates the need to refer to MH services. Some participants noted the difference between professionals regarding GP involvement for referral to a mental health specialist (Focus group 1):

**Focus Group 1**

*P2 (C): Because we all work in various systems like I can't accept a referral in the Lewisham child and young people's service.*

*R: Yeah.*

*P2 (C): without a proper referral a form completed by the GP.*

*R: Right.*

*P1 (Psychol): Whereas I can accept self-referrals as can L and actually that's what was going through my mind when you were talking to him was I was wondering if we could make the availability of psychology/counselling young people's counselling service more accessible to young people. Some kind of information may not be getting out that people could self-refer if they feel ok about doing that. Because of course some young people want to see the GP first to make sure that their medication is right or whatever whereas there may be others who've done that bit of the consultation and thinking about their mental health.*

Two participants identified a tension between the role of the new graduate mental health workers and Mental Health Trust policies (Focus group 1). From the PCT perspective, graduate mental health workers were to see patients who had self-referred for social prescribing but the Mental Health Trust wanted GPs and nurses to have contact to manage the clinical responsibility associated with vulnerable patients. A minority of participants agreed that primary care has access to different services but that long waiting lists for talking therapies often leave practitioners feeling frustrated (Focus group 2).

***Organising theme: questioning the validity of the quality indicators***

This theme was developed from taking a critical view of the structural issues affecting the implementation of the quality statements. The following basic themes represent an attempt to deconstruct the issues surrounding communication systems, power differentials and responsibility: implicit in general practice, communication is problematic, competing interests and difficulty in keeping information up to date.

### **Basic theme: Quality indicators are implicit in general practice**

Some participants strongly believed that many of the quality indicators already featured in their everyday work:

#### **GP 2 Interview**

*GP2: I mean I think I think they are important but I think I mean as I said in the beginning there's quite a lot that I hope would hope that we do already.*

*R: Ok.*

*GP 2: But I can only speak for myself.*

A minority of participants in focus group 2 acknowledged that young people may anticipate being stigmatised when seeking help for mental health problems. GP2 and GP3 felt strongly that PCPs were aware that young people might be embarrassed and needed reassurance that mental health problems were common<sup>10</sup> and that PCPs would ask a young person about their relationships and support network<sup>11</sup>. GP2 and GP3 felt that PCPs often discussed self-help options with patients<sup>12</sup>.

#### **GP 3 interview**

*GP 3: ...I mean number eleven<sup>13</sup> is sort of touching on the fact that people would want advice. I mean I'm really surprised that people don't, don't do number eleven anyway it feels like you know what else will you do really if you don't discuss ways you can overcome stress what else do you do?*

One participant from the GP focus group felt that PCPs might dislike being told to incorporate the quality statements into their practice:

#### **Focus group 3**

*P1 (GP): ...some GPs might I suppose possibly resent a bit being told to suck eggs. If we have to tell people not to judge negatively and I think that we hope that we don't do that and it may be that from feedback we know that somebody's doing it but I think some people might be a bit aggrieved.*

Informing young people at the beginning of the consultation about confidentiality protocols<sup>14</sup> was considered an implicit part of general practice by some of the participants in focus

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<sup>10</sup> Quality indicator 14) - Primary care practitioners should appreciate that young people can feel embarrassed to seek help and should reassure them that mental health problems are common

<sup>11</sup> Quality indicator 15) Primary care practitioners should ask questions about a young persons' relationships and support network

<sup>12</sup> Quality indicator 11) Primary care practitioners should discuss ways that you can help yourself overcome the symptoms of mental health problems

<sup>13</sup> Quality indicator 11) Primary care practitioners should discuss ways that you can help yourself overcome the symptoms of mental health problems

<sup>14</sup> Quality indicator 13) Primary care practitioners should have a strict confidentiality policy, which they state, at the beginning of the consultation preventing them from disclosing information to members of the young person's family.

groups 2 and 3 and by GP2. These participants also felt that they already discussed other treatment options <sup>15</sup>.

Some of the participants felt that PCPs should provide information to young people about what to expect following a referral <sup>16</sup> (Focus groups 3 and 4 and GP1). However, a GP participant from focus group 4 provided an alternative view and felt that this was already done by PCPs in the practice:

#### **Focus group 4**

*P1 (GP): the second thing is that regarding the psychologist service and counsellors do have the leaflets that we give to patients when we make an initial referral so they know what to expect when they go to the meeting.*

Some participants in focus group 2 felt that although PCPs might feel that many of the quality indicators were implicit to general practice they were aware that young people may not feel that this was the case:

#### **Focus group 2**

*P2(GP): I mean that has got to be in place and is for professional reasons because if we're not confidential our necks are on the line and we're up before our own professional bodies so it is there but our failing perhaps is to communicate to young people that anything they say to us really is confidential you know.*

### ***Basic theme: competing priorities***

All three GP interviewees felt that there were other health problems that they had to deal in addition to managing mental health problems. GP3 highlighted the tension between spending time counselling in consultation and having the time to see patients:

#### **GP 3 Interview**

*GP3: I mean people want more advice and it's a real tension isn't it which is why actually sometimes counselling by doctors if that's called counselling is much more active. We tend to do talking we tend to they want to talk and yet you know the whole time we're told actually we should be in clinic and how much advice should you give?*

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<sup>15</sup> Quality indicator 5) Primary care practitioners should discuss other treatment options before prescribing medication to a young person.

<sup>16</sup> Quality indicator 10) if making a referral primary care practitioners should provide information for young people about what to expect at the first appointment.

### **Basic theme: difficulty of providing up-to-date information to patients**

The GP focus group agreed that information was difficult to keep up to date. This was also felt by some of the participants in focus group 1 and two GP interviewees (GP1 and GP3). Participants suggested strategies for finding appropriate information such as relying on key members of staff known to have up to date information of local youth services and gleaning feedback from patients about their experience with local services:

#### **Focus group 3**

*P1 (GP): I think the information about local services I mean or social services is a useful thing always. The thing is it changes they come and go so quickly. And what we tend to do or I tend to do is ask our counsellor here who knows a large part what do you recommend for a teenager who's got this and that? And ask her where to send them you know in terms of databases that are kept up to date.*

The GP focus group agreed that it was unrealistic to ask PCPs to keep young people up to date with the progress of their referral appointment<sup>17</sup>. They supported one another's point of view with reasons and began to laugh amongst themselves as a final endorsement of their shared views:

#### **Focus group 3**

*P2(GP): I'm not sure about number 9 I am not sure how realistic that is or who would be doing that, who would be keeping the patients, the young person up to date with we tend to make a referral and then you know I usually say to the patient if you don't hear anything within a time span then get back to us at the surgery but I wouldn't usually do any more than that and then leave it to the patient to keep an eye on it and if they don't get an appointment I'd expect them to either come back and see me to say they didn't get an appointment or to chase it up themselves. Not sure how realistic it is for us to be thinking about that.*

*R: Do you agree with that or?*

*P3 (GP): Absolutely yes I think we can't really be responsible for chasing up everybody's appointments. They have so many.*

*P1 (GP): You can have a system in place whereby they are informed I think it wouldn't be us because normally we refer people and that's dealt with but I mean there could be a system whereby who ever you've referred them to will send sort of periodic identification of what ever happened to number 7093. [Group laughing]*

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<sup>17</sup> Quality indicator 9) for referrals within the GP surgery, primary care practitioners should keep the young person up to date with the progress of the appointment.

Keeping patients up to date with their appointments was also considered unrealistic by other participants (Focus group 1, GP1 and GP3). The difficulty of keeping information up to date is linked to problematic communication between primary care and outside agencies (presented below).

***Basic theme: communication is problematic between professionals***

Communication regarding referral outside agencies was considered problematic by some participants (focus groups 1, 2 and 3 and GP1). One GP participant felt strongly that PCPs were often not kept up to date about a young person's progress between the initial referral and discharge (focus group 4). This illustrates a link between communication and interface issues with mental health teams.

Communication within the practice was also considered problematic by some participants (focus group 2 and 4). In focus group 2, a minority of participants felt it might be difficult for all practitioners to attend the mental health team meetings at the practice. However, this was challenged by a practice counsellor who felt strongly that all therapists should be present:

**Focus group 2**

*P5 (PM): What I was thinking the other issues are and I was thinking about and I've written it down is that the communication between who you are referring onto and when their going to see that person I think there sometimes maybe a breakdown in that and I know that with the team that we have working here there not all that we just have [name of clinical psychologist] who's a child and the others are counselling and then an adult psychologist but they all work very different individual styles some do keep the GPs informed of what's going on some don't so even in-house there are different levels of feedback so if there is a GP holding a patient at that time they may not always be able to give the information as to the waiting list and I don't know what its like when we refer outside of the services either how well the information is kept.*

*P6(C): Well do you have a practice meeting?*

*P5 (PM): We have mental health team meetings.*

*P6): How often are they?*

*P5): Monthly.*

*P6): Well at that monthly meeting that ought to be something that people can communicate*

*P5: It's just the mental health team we don't have the entire practice working.*

*P6: They should all be all the therapists should be here.*

*P5: Well the therapists can't.*

*P6: All the therapists should be there.*

*P5: They should.*

*P6: And any of them that wants to know what happened to their patient should make sure that it gets discussed at that meeting*

*P5: It's not that easy logistically I'm afraid they.*

*P2 (GP): There's always a GP as well that's present.*

*P5: There's always a GP present and they're responsible for taking back to their team but bearing in mind these aren't practice employed entirely they work in other areas so if someone is working in north London they're not going to try and traipse across here to attend a meeting when they've got clinics to hold.*

Two GPs in focus group 4 noted that communication within the practice was difficult. This however was challenged by a psychologist who informed her GP colleagues that she had updated the computer system to allow members of the team to access information within the practice:

#### **Focus group 4**

*P7 (GP): Yeah ok that is fine I mean yeah they've realised that confidentiality is an issue and I just feel like psychologist that cannot know about what is going wrong during the consultation that psychologist or maybe in with the CPN or whether - unless we receive a letter from the psychiatrist telling us what is going on so this must take long time... from the patients maybe we wouldn't know by that time so it is very difficult to keep updating people's ...*

*R: Anything to add to that - do you agree with that?*

*P1 (GP): yeah I mean we tend, we all work at different times so there's no way of communicating amongst us. If they do see the CPN then M uses the computer so at least we can see in the consultation, a computer consultation record that a patient has been in or DNA [did not attend]'ed an appointment and what they talked about, in terms of counsellors and psychologists we don't have that record so we have no idea if they are turning up to their appointments or not.*

*P5 (Psychol): Actually we do now have*

*P2 (PSM): That has changed. We have a record of attendance but not actually the consultation*

*P1: But if you go into the computer we can't say that they DNA'd her appointment.*

*P5: I've changed that - it has been an ongoing thing but yeah*

## **Global theme: Examination of skills**

The task of implementing the quality indicators was associated with examining professionals' skills. Managing mental health problems in primary care was noted as difficult. This task was even more challenging when dealing with young people. In addition, PCPs differed in their level of confidence. See figure 11 on page 201.

### ***Organising theme: practitioners are challenged***

Although the focus groups aimed to assess PCP views on the quality indicators specifically, the discussions often revolved around the challenge of managing mental health problems in young people. The following basic themes represented the issues reported: prescribing medication is problematic, negotiating confidentiality is difficult and young people are difficult to engage.

### ***Basic theme: prescribing medication as problematic***

Prescribing medication for mental health problems was often considered to be the only option for PCPs (GP1 and GP2 and one participant in FG1). GP3 felt strongly that GPs needed better guidance on mental health care for young people due to the changing recommendations on prescribing anti-depressants for under 18-year olds:

#### **Interview 3**

*(GP): I mean I wouldn't but if I was to try and prescribe an antidepressant to under whatever it is 18 it would immediately flash up and say this is no longer recommended but of course you know three years ago that wasn't the advice and so I mean I think it's, it's absolutely true but actually I think that you know this is changing waters and whose to know in two years time that something we haven't found that actually this is all a bit of a mountain and actually it is quite appropriate to use it blah, blah, blah.*



GP participants from different focus groups (3 and 4) felt that PCPs should not prescribe medication for young people below the age of 20. Participants from the GP focus group all agreed that medication would be suitable for a young person in their early 20's. This illustrates the importance of the distinction between younger and older individuals.

#### **Focus group 4**

*P6 (GP): In a way I'm kind of amazed that the issue arose the GPs were prescribing drug like SSRI's [Selection Serotonin Reuptake Inhibitors], I personally wouldn't have the nerve to make a decision in that age group, perhaps even anyone under 20.*

Two participants felt that PCPs should discuss other treatment options before prescribing medication <sup>18</sup> (GP1 and one participant in focus group 2). A youth worker in focus group 1 noted that young people avoid their GP because of fears they will be offered medication:

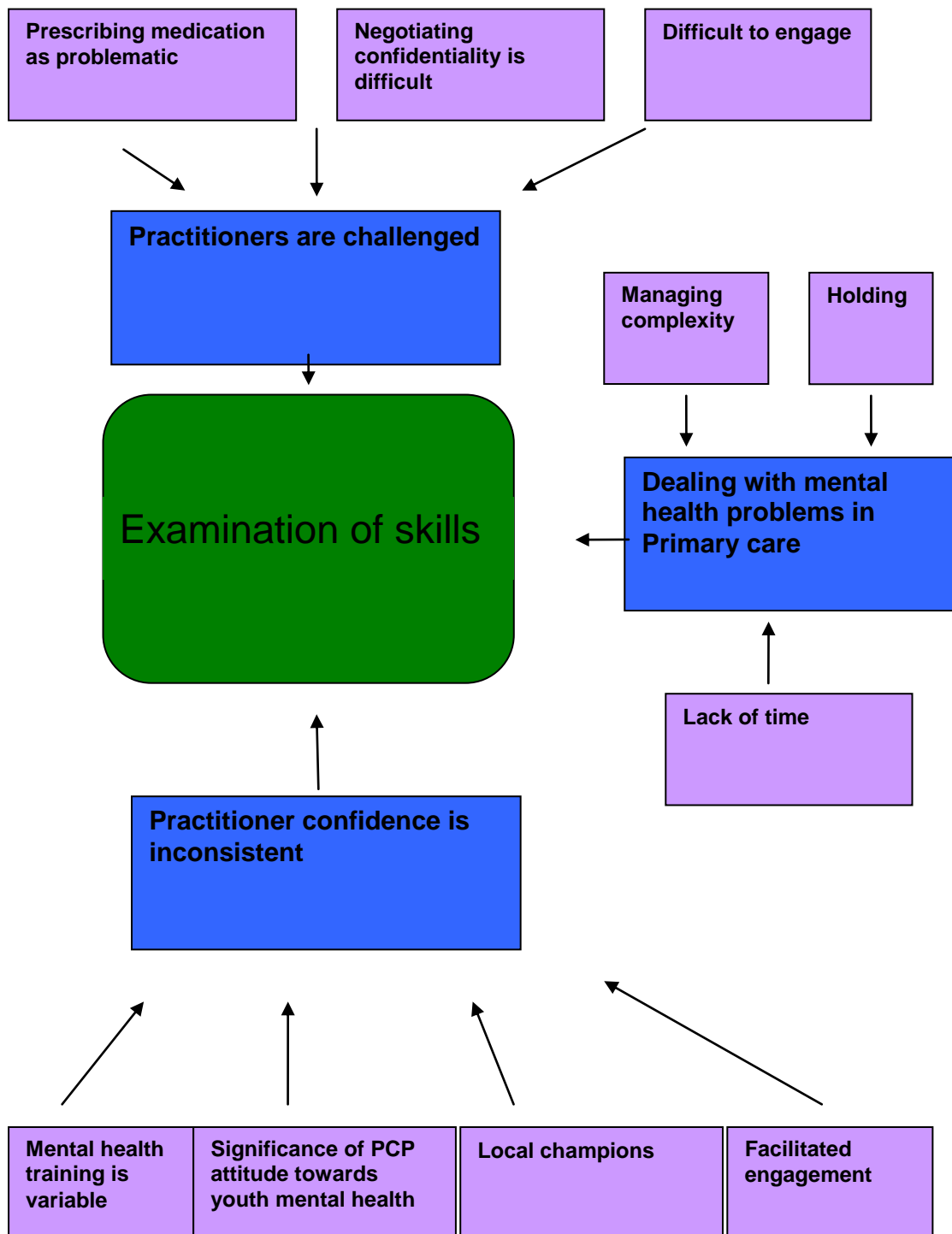
#### **Focus Group 1**

*P2(C): ...I think with the work that I do I mean at least 70% of the clients that are referred to me do not want to see a GP because they feel they're going to be offered medication and their not sure about medication do you know what I mean? So they don't really want to see a GP and they make you know somewhere upwards in the third of the fourth or the fifth week that comes up. And if they're scared for some reason because maybe they've been offered it before I'm not sure but sometimes they come from other agencies and that's one of the things they asked me you know do you are you going to give me medication?*

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<sup>18</sup> Quality indicator 5) Primary care practitioners should discuss other treatment options before prescribing medication to a young person.

Figure 11: thematic network 2 - Examination of skills



### **Basic theme: negotiating confidentiality is difficult**

Some of the participants felt that PCPs are often placed in a difficult position when discussing confidentiality with a young person (Focus groups 2, 3 and 4). Confidentiality issues for PCPs included situations when a young person is self-harming and being asked to disclose information about the patient for insurance purposes. One GP participant in focus group 4 felt that counsellors often don't inform GPs of their patients' progress because of confidentiality between counsellor and the patient. On one occasion, the co-facilitator challenged a youth-worker about her stance on negotiating confidentiality. This required her to further explain her views to the group:

#### **Focus group 1**

*P2(C): Yeah there is a clause that's always gonna to be there [sic] with number fifteen [quality indicator 15] and I think that's important for the young person to know but because for me it's like everything outside of that is confidential do you understand but if you are going to harm yourself or you're going to harm somebody else I do need to speak to somebody else before I speak to somebody else I will be letting you know that I'm going to do that but, but that that's the truth really so that that might as well be brought in the room.*

*Co-facilitator: What if the patient said well actually I don't want you speaking to that person about it what would you do then?*

*P2: Yeah I would have to be really.*

*Co-facilitator: That's not confidentiality though really is it I know you were saying about the different levels of confidentiality but confidentiality is confidentiality regardless of what situation you're in.*

*P2: Yeah but because I'm in a working environment this is this is part of the protocol to with my job and responsibility I can't go outside of that so I'd have to really explain that even if that you will know I'm not going to speak to somebody before I let you know I'm going to say well look you know I have to speak to my supervisor or I have to speak to somebody else because I haven't got a choice with that I can't work.*

*Co-facilitator: Who, who says you have to?*

*P2: But you have to you have part of.*

*P1 (Psychol): Well is that the guidelines.*

*P5 (GP): It's part of the remit of the job.*

P3: Yeah.

P2: You don't we don't accept the job without accepting that.

P5: Can I just say sorry that that is an extremely rare circumstance.

P2: I've never had to do it.

### **Basic theme: difficult to engage**

Some of the participants in focus group 1 were aware of the age difference between themselves and young people. GP 3 felt that engagement of a young person is representative of how comfortable the practitioner feels. GP1 felt that young people often judge a practitioner on how they interact with a young person. Focus group 1 agreed that young people were a difficult group to engage. When one participant (a counsellor) spoke about her lack of skills to hold a young person the group all began to laugh and another GP participant supported her by acknowledging the difficulties of interacting with young people:

#### **Focus group 1**

*P3 (PC): Well I would like to have more a little bit of training in working with young people because although I've kind of perhaps put a slightly positive gloss on it because actually as it happens the young people I'm working with at the moment are doing quite well and have engaged and they're continuing I've actually noticed that in the past and I'm sure it would happen again that I haven't always been able to hold a young person and that they have disappeared from my contact after perhaps one or two sessions and I feel that some of that maybe to do with me and my engagement and I would like to improve that so I have been on the lookout for you know training short training to help me with that.*

*R: Anyone else that's different or some experience or with regards to training?*

*P5 (GP): Not so much regards to training but a lack of engagement! (Group laughing)*

*R: Why is that?*

*P5: well its just I think it's a difficult it's a difficult group I mean I think what people all groups have their challenges but I think there are and it may come from some of the issues that A and L have touched on in terms of kind of difficulties in or the varying difficulty in actually sort of initiating the contact and one doesn't always get the response right perhaps one doesn't always have time may be appreciate the difficulty of that first step so I think that the second or the comeback and lets talk about it again doesn't always happen.*

P1 (Psychol): No.

P5: So you're not alone (talking to P3)

### **Organising theme: practitioner confidence is inconsistent**

Throughout the data collection and analysis phase I observed that participants often displayed vastly different levels of knowledge and confidence regarding the management of young people's mental health problems. For example, two GPs in focus group 4 displayed very different approaches to the issue of managing mental health problems in young people. One GP was more hesitant and seemed to be explaining his thinking about the topic to the group. The response from the other GP was much more confident as she explained to her colleague and the rest of the group the referral pathway she would suggest for a young person with mental health problems:

#### **Focus group 4**

*P3 (GP) its true there has been recent talk recently, now when I look at the guidelines and they tell any child less than 16 years of age most of them are..... you're not allowed to prescribe. And then again in secondary care as well then again they have seen a few patients at that age with depression and would it be similar in secondary care with also therapies then they are still having problems and they come back to primary care and you should you don't know what to do really...*

*R: what do people think about that?*

*P1 (GP): in this area if they're under 18yrs old and if they are involved in depression and mental health you can refer them to (name of an in-patient unit) and they will see them at the age of 18 or if something that you think maybe a child psychotherapist (says name) she can deal with that otherwise if it is something that you think may be more urgent or need a bit more input from a multi-disciplinary team then refer them to (name of CAMHs) and they are seen by a multi-disciplinary team.*

The differences in confidence were illustrated by the following basic themes: mental health training is variable, significance of practitioner attitude, local champions, and facilitated engagement.

### **Basic theme: mental health training as variable**

Some participants believed that GPs vary in the level of mental health training they receive (all four focus groups and GP3). There were also divergent views between the participants on what constitutes a sufficient level of mental health training for GPs:

#### **Interview 3**

*GP: Um indicator five I mean you know all primary care practitioners do have mental health training so you know it's a stupid indicator really we all have we all it is part of being a GP we can't be a GP without having some mental health training. It's fine to say fine yeah of course we should but we do I know that number five is not a problem but it's not really a indicator because everybody will pick it I mean everybody will achieve it because all the GPs have it.*

#### **Focus group 1**

*P5 (GP): ...it is not even a core indicator of GP registrar training and I think I think it's an a yeah I don't well I it's difficult that it depends on your trainers I suppose. If you have a kind of really switched on trainer you could acquire what you need in terms of but I'm a bit dubious I think that we need more posts in community psychiatry that are specific for GP registrars...*

*P1 (Psychol): Training ...*

*P5: Within their three-year GP registrar rotation I think it's a real deficit if you don't have some psychiatric exposure and that so I think [sic] it is very beneficial to have that.*

Some participants recognised that there was a lack of formal mental health training opportunities (Focus group 1). A minority of participants in focus group 2 felt that mental health training should be targeted towards a multidisciplinary audience within the practice. Two GPs felt that quality indicator 2 'all primary care practitioners should have mental health training' needed better definition (GP1 and GP2). Some participants believed that personal interests play an important role in determining whether PCPs would attend mental health training:

#### **Focus group 3**

*P3 (GP): some people may have a lot more in that some of us GPs may have done a 6-month attachment to a psychiatry unit which might have involved adolescent psychiatry. Some of us may have come through without any long-term psychiatry attachment apart from what we've done as medical students. So it does vary we all come with a slightly different background of training and psychiatry is not a compulsory part of training to be a GP in terms of what do you do after you've qualified. It certainly is a compulsory part of your medical student training but there after it may depend on your personal interests.*

A minority of participants in focus group 1 believed that learning from colleagues with an interest in youth mental health was an important source of education. Some participants felt that PCP confidence in handling youth mental health could be improved through training:

### **Focus group 2**

*P8 (PN): I think that a lot of the stuff that N was talking about and everyone else is talking about is useful but I think from a practice nursing point of view that because I had that experience of you know a year of having some sort of training that I don't feel particularly scared of it so if someone comes into see me and they are in a real state. I know fast enough whether I need to act on it now you know because you see people like I've got a ten minute appointment do I act on it now do I need to do something now are they ok can I bring them back next week whereas if you haven't got that experience you don't know and you could miss something so.*

### **Basic theme: significance of PCP attitude towards youth mental health**

Some participants felt that a PCPs response to a young person was highly dependent on their willingness to deal with mental health problems (Focus groups 1, 2 and 4)

#### **Interview 1**

*GP: basically changing our behaviour so that it refers to usually talking about teenagers or that come in without a booked appointment you're more prepared to try and deal with the problem then.*

*R: Rather than say...*

*GP: Rather yeah because you're not going to get another chance.*

GPs ability to engage a young person was related to how comfortable they feel with young people (GP1 GP3).

### **Basic theme: local champions**

Participants across the entire data set gave examples of instances where they felt they were already implementing the quality indicators such as developing a young patient questionnaire and commissioning young person's health projects:

#### **Interview 2**

*GP: Well I mean it worked for us because M (young person's health worker) we employed M. As a group of practices we employed him.*

*R: Oh I see right.*

*GP: And then he basically was self-perpetuating you know he went off and one of his very,*

*very good skills was networking. And he managed to link with all sorts of things and get money and funding. I have no clue where he'd done it from but it's become a sort of self-fulfilling prophecy.*

Advertising the availability of help for young people with mental health problems in the waiting room (quality indicator 1) was considered 'easy to do' by one participant. Some participants felt that practice change could be achieved through multidisciplinary clinical meetings. These participants also believed that it was important to have an interested practitioner to take the lead with mental health team meetings and youth mental health initiatives (Focus group 2 and GP1).

### **Focus group 2**

*P6 (C): But you can only build that in by what (name of P2) was also saying earlier having the mental health clinical meetings on a regular basis within the practice which are you know led by a lead person and all the practitioners going to them and discussing patients.*

*P8 (PN): But there has to be someone there already who has an interest to even begin to do that focus groups do you see what I mean? Whereas if you're not a practice where it's not your interest at all it is not it's not going to happen.*

*P6: No but I think there is there are now primary care team meetings that can be devoted to mental health on a regular basis.*

*P8: If they want to that's what I'm trying to say I'm trying to say that some practices just don't that's, that's not an interest for them*



### **Basic theme: facilitated engagement**

Some participants felt comfortable developing a rapport with young people (Focus group 1). This was disclosed in response to an earlier discussion about the difficulty of engaging young people:

#### **Focus group 1**

*P4 (PCMHW): I think because I am younger quite possibly you know I may be about to build up you know a better rapport while I'm seeing a younger person. I can't say that conclusively because I haven't had that much patient experience because I haven't been in post that long but I think the patients I have had it seems to work slightly better. You know I can sort of talk the lingo a bit more I suppose be a bit more I suppose a bit more down to earth and possibly approachable.*

GP2 felt that enabling self-referral to a young person's health specialist could be an effective way to engage young people, as they would not have to go through the GP:

#### **GP 2 Interview**

*GP 2: And we now have (name of youth health worker) and she's very, very good because that the advantage of that is that they can self-refer so you know we often get the parents come in and saying I'm worried about my teenager who doesn't want to come.*

### **Organising theme: dealing with mental health problems in Primary care**

Participants referred to concepts regarding the general management of mental health problems in primary care. These are represented by the following basic themes: managing complexity, holding and lack of time.

### **Basic theme: managing complexity**

There was concern about the tension between 'medicalising' social problems and making sure mental health problems are appropriately treated. Some participants from across all focus groups believed that PCPs often find themselves in the difficult position of managing the 'grey area' between mental health and housing issues and substance abuse. One GP participant felt that the issue of managing the association between mental health and drug problems was exacerbated by secondary services often excluding young people on the basis of substance use:

#### **Focus group 3**

*P3 (GP): I think there's always a big difficulty in maintaining the, well recognising the grey area between mental health problems and just social problems because a lot of people will come in with something that is essentially a social problem but present it as a mental health*

*problem. I'm depressed because of my housing problem for example and when really the primary issue is one of housing. I think the problem with this is in encouraging too much to present mental health problems is missing out when the solution is really a social one. I think that's where the social prescribing thing I think covers that sort of grey area a little bit.*

**Basic theme: holding**

Some participants acknowledged that PCPs adopt a strategy of 'holding' patients whilst waiting for a referral to counselling or secondary services (Focus groups 1, 2 and 3). A practice counsellor suggested that patients should be offered 'regular holding sessions' to ensure they receive appropriate and timely help.

**Focus group 3**

*P1 (GP): Especially referral times, I think availability of counsellors and specialist counsellors and I think what GPs do isn't always appreciated. But what I do now is that we do take on referral to the availability of the services so even if somebody there is no... Orthopaedics isn't available then people will have to sort of hold them there for a bit a bit longer and in mental health it happens even more. You sort of hold onto stuff if there isn't a place to refer to...*

The GPs in focus group 3 agreed that referral times should be made as short as possible for young people (quality indicator 8). This was also supported by GP2. However, GP3 and a practice nurse in focus group 2 felt that this should apply to patients of all ages and not only young people.

**Basic theme: lack of time for GPs**

Some participants felt that their response was limited due to lack of time with each patient (Focus groups 1, 2 and 3). These participants recognised that other mental health workers in primary care and those in secondary services have longer appointments available to them:

**Focus Group 3**

*P1 (GP): ...it depends on resources to some extent um and I suspect that not many GPs would have the time to devote an hour-long session times 8 or whatever to, for people who need it. So I think that's why we do tend to refer on.*

## **Global theme: Importance of commissioning, incentives and guidance**

PCPs debated the role of commissioning, incentives and guidance regarding the potential success of the quality indicators. Many felt that the quality indicators would need to be supported at national, regional and practice level in order to be implemented (see figure 12 below).

### ***Organising theme: National and regional level initiatives***

Participants spoke about the impact of national and regional initiatives and their effect upon implementing the quality indicators. These are represented by the following basic themes: funding role of the PCT, significance of the quality and outcomes framework and the impact of guidance on practice.

### ***Funding role of PCT***

Participants agreed that access to funding determines which services can be provided (focus groups 2 and 3). This was also supported by some participants in the other focus groups. GP1 felt that the commissioning role of the PCT would be crucial to the implementation of the quality indicators:

#### **Interview 1**

*GP: Yeah they'd need to play a role yeah because it's the way these things are commissioned and that so you know in indicator six<sup>19</sup>*

*R: Yeah.*

*GP: For instance as I say I think it is you know it'll take a very long time to realise that by having you know appropriate level and expert provision within each practice but what it could do was, was commission a service model in which you know wherever possible and felt appropriate by the client.*

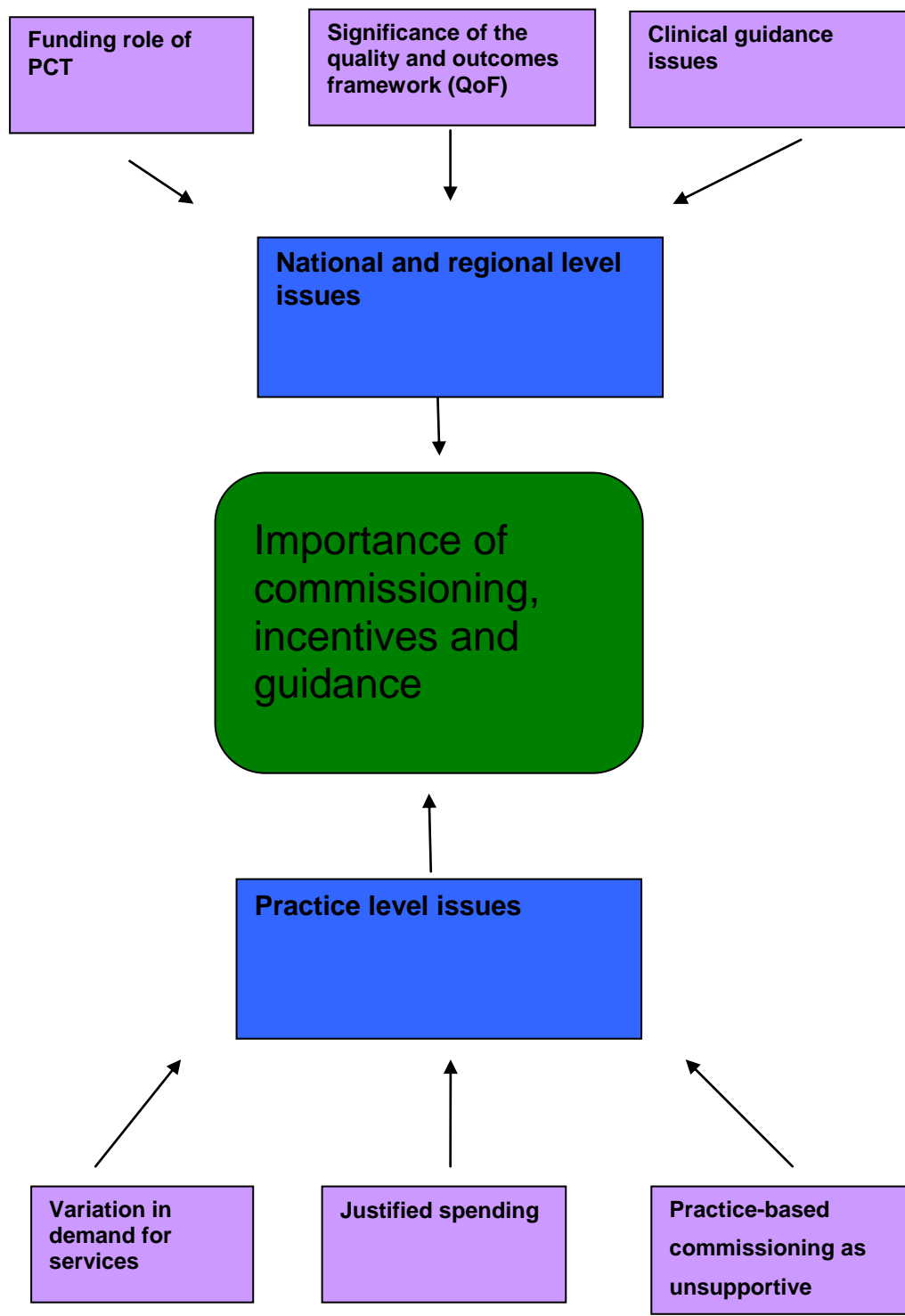
*R: Yeah.*

*GP: Consultations by the CAMHS people.*

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<sup>19</sup> Quality indicator 6) Young people should be able to see a mental health specialist at the GP surgery.

Figure 12: thematic network 3 - Importance of commissioning, incentives and guidance



In focus group 2, services funded by the PCT were hotly debated. A clinical advisor suggested the PCT's commissioning role was to commission mental health awareness training and self-help skills to reduce the burden on primary care. However, this was strongly challenged by a practice counsellor who asserted that putting money into preventative work reduces the ability of PCTs to provide timely and appropriate access to services:

**Focus group 2**

*P3: And there's all the stigma that goes with that of your perceptions about what that means and so on but actually there's an awful lot of issues that are about mental health and keeping healthy that can actually be taught and are freely available and actually what again what were trying to do with practices is, is to and also community pharmacists and people like that is actually for them to be able to have a range of options that don't demand the medical model ticket if you like, like leaflets and books and tapes and local resources which is absolutely right but at the moment there's no network to inform practices of what those resources actually are in Lambeth you know those kinds of things that people can undertake without necessarily yeah.*

*P6: I beg to disagree I am afraid*

*P3: No no go on then*

*P6: I think it's not taking mental health seriously to be offering those sorts of things for imagining that sort of preventative work is going to resolve things. If we take it seriously we should be basically saying every patient has the right to access to see a therapist or a practitioner I don't care who it is but a practitioner who is going to actually talk to the person and take the problem seriously to treat them themselves or provide treatment and they should have access to that person within two weeks and have access to treatment the treatment of their choice within four weeks and the PCT needs to make those two things absolutely clear that that is the patient's choice and the patient's right and if they don't get it then they can complain.*

The same two participants from focus group 2 challenged one another regarding the disproportionate PCT spending on SSRIs compared to talking therapies:

### **Focus group 2**

*Co-facilitator: I've been on medication myself and it helped some of the feelings but often with the depression you're the things that are happening in your day to day life is still happening so it doesn't change anything so when you're waiting a year for you know whatever*

*P6 (C): and as a PCT we are spending one and a quarter million pounds on SSRI antidepressants we're spending three quarters of a million pounds on talking therapies.*

*P2 (GP): Exactly.*

*P3 (CA): But I don't think it's that clear cut personally.*

*R: Expand.*

*P3: I think that you know for a lot of people actually medication has been a major value to the way in which they manage things and it is not either or and I think where it can help is enabling you to work on the issues that you have in a way that perhaps you couldn't without it. Now there will be people for whom medication isn't right and doesn't work but there are others who actually don't get anywhere without it and so I think we're talking about a spectrum here.*

*P6: NICE guidelines say you should offer the talking therapy before you offer antidepressant and that's not happening.*

*P2: For mild depression.*

*P3: for mild depression that would be entirely agreed.*

*R: But you're saying it is not available.*

*P6: It is happening the other way round.*

*P3: Well it is at the moment.*

Some participants expressed the view that it was desirable to improve access to talking therapies for young people <sup>20</sup> but that doing so was made more difficult because of low availability. The GP focus group agreed that the availability of talking therapies was directly related to funding opportunities. This was also supported by GP1 and GP3.

### **Focus group 3**

*P2 (GP): I think the referral times being as short as possible is, in an ideal world but things like that are very difficult because referral times are always not always but often much longer than you would want them to be. But that's often a problem of lack of funding and how you address those sorts of things*

GP1 felt strongly that it would be very difficult to secure more funding for people with common mental health problems because PCT spending favours people with serious mental health problems. Participants believed they would be hesitant to advertise treatment <sup>21</sup> when the availability of psychology services is low. Participants gave examples of short-term mental health initiatives enabled by PCT funds that were often withdrawn (e.g. social prescribing projects). One GP in focus group 2 recognised that PCT funding for young people's mental health projects could be made possible through lobbying the PCT.

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<sup>20</sup> Quality indicator 7) Access to talking therapies needs to be made easier as an alternative to medication for mental health problems.

<sup>21</sup> Quality indicator 1) Primary care practitioners should advertise that they are available to help young people with mental health difficulties.

**Basic theme: significance of the quality and outcomes framework (QoF)**

Some participants felt that locally enhanced services were considered as an option to improve availability of talking therapies but were also problematic as appropriate funding levels would still need to be approved. One GP felt strongly that PCTs across the country have been slow to support local enhanced services for depression:

**Interview 3**

*GP: So it's a resource issue it's not a indicator well it could be a indicator I mean if the money came with the indicators then that would be great if we but I've got the feeling that what they'll say is that well you can't you can't get the enhanced service and I suppose the idea is to bring the money in and then say well now you buy the buy it in.*

*R: Yeah.*

*GP: But actually the reality is again I suppose it's about how much money they're going to pay for it.*

GP1 believed that individual practices might be reluctant to consider enhanced depression services as they could create more work for the practice:

**Interview 1**

*GP: Well the reason for doing it for having a locally enhanced service which you can then tailor to your resources which is why the national one if difficult would be to try and improve quality. You know quality of care obviously and many people want to do that. What would make individual practices reluctant do it is that they overcook the cake in these locally enhanced services. We find that this incentive where you are having to do too much monitoring too much stuff and it starts seeming like a barrier.*



It was felt that recruiting financial support for an initiative was an important way of getting PCPs to incorporate the quality indicators into their practice. However, participants noted that there are no quality indicators that specifically related to young people's mental health in older and subsequent versions of the Quality and Outcomes Framework. That there was no financial incentive was considered a barrier to implementing the quality indicators. GP participants agreed that young people would be a difficult group to recruit for the QoF patient experience indicator (Focus group 3):

### **Focus Group 3**

*R: so what did things like the general medical services contract, would that have an impact? How does that play a role in thinking about these? Or does it not affect it?*

*P3 (GP): Not this one.*

*P1 (GP): Not a great deal because there are no quality outcomes that are directly related to this um a couple of contracts ago we were equipped to be able financially to be able to employ counsellors and so on ourselves but they stopped that. They the conservative contract they sort of stopped that so with this contract we're really stuck with services that are provided by the PCT.*

Some of the participants in focus group 2 noted that at the time of the focus groups were conducted (in 2005) depression had not yet featured in the QoF. In response to this view, a GP participant from this group asserted that focussing only on QoF indicators compromised patient-centred practice:

### **Focus group 2**

*P1 (GP): I don't think it influences what we do at present and whether it's going to influence service unless there is funding behind it I don't think including I'm mean it would be interesting to see what they include as the QoF in terms of it the main weakness with most of the measurements is the fact that you know it's there rather than what do you do I think depression and anxiety is such a complex and often individualised area but it's a it's a very blunt instrument even if it does come in an certainly isn't going to be individualised treatment in fact what it intends to do is make you not be able to individualise treatment because its so blunt so they say have you done x y and z well it doesn't matter is y and z aren't particularly appropriate you need to do x y and z because that's, that's how they measure so it's a very blunt instrument and I think at times can interfere with individualising treatment at present.*

### **Basic theme: clinical guidance issues**

It was suggested that changing practice requires practitioners that are confident enough to 'think outside of the box' dictated by clinical guidelines. Some participants believed that fear of litigation discouraged PCPs from relying on their own interpretations of clinical guidance (Focus group 1 and GP3):

#### **Focus group 1**

*P1 (Psychol): Well if you don't follow the guidelines and something happens to this young person which can happen to anyone I mean let's say somebody does take an overdose or whatever which maybe they were going to do anyway. But as practitioners I mean this is partly why (name of PCMH) is in such a difficult situation at times being supervised by my mental health trust which is a huge trust but it's developed all these risk screenings and often it's to protect the practitioners as much as the client because practitioners and GPs are in a very vulnerable position in this respect after taking the primary medico-legal responsibility for that patient client. I'm not taking it the GP is and so they're the ones who are most exposed to those kinds of pressures. So you know if a GP is not confident and that's why you know we are glad we have (name of GP) here if they're not confident of mental health issues then they'll be inclined to not listen to the person but tick the boxes and prescribe the medication.*

A GP participant in focus group 1 felt strongly that clinical guidance requires PCPs to ask a series of questions to ascertain the number of symptoms for diagnosis but that for the service user it may seem like they are 'firing questions' and not listening.

Some participants noted that the general medical service contract largely controls service provision. However, GP participants felt strongly that practitioners do not only conform to government policy but also decide themselves whether or not to incorporate a new initiative into practice. One GP participant in focus group 1 told the group he would rather not get the money linked to following a medical model of depression but be able to be creative and imaginative about what to offer young people:

#### **Focus group 1**

*P5 (GP): Well my view of the GMS contracts in terms of say for example the enhanced depression services.*

*R: Yeah.*

*P5: Is that they straightjacket you into thinking in a particular way about depression.*

*P1 (Psychol): Yeah.*

*P5: And I'm fed up with ticking boxes to be honest with you and I'd much rather not earn the extra points and the extra money from what is a very very medical model of depression and a very medical model of, of, of managing an illness that, that that's any rigid any rigid guideline or template will tend to have and I think it's much better to be more creative and imaginative about, about the range of things that you can offer so I would I would doubt that we would fit here in this practice that we would fit in to, to enhanced depression services because I think I think there you know you have to be slavishly data collecting and, and slavishly following guidelines which I think are of some you know.*

*P1: Questionable value.*

### **Organising theme: Practice level issues**

Participants spoke about practice level issues and how they may impact upon the implementation of the quality indicators. These are represented by the following basic themes: variation in demand for services, justified spending and practice-based commissioning is unsupportive.

### **Basic theme: variation in demand for services**

Some participants felt that although open access should be offered, when patients did self-refer, the mental health team in the practice could not cope with demand and were forced to close the waiting list (Focus group 1):

#### **Focus group 1**

*P5 (GP): I think you know we haven't got true open access here we did have for a while have true open access to the mental health team we had to stop that because although the people coming were entirely appropriate we couldn't cope so again that's why GPs or nurses or are filtered but I don't think that's the ideal situation because I think if you did have a referral form at the practice reception that that would be the best alternative. I really think people should be able to pick up a form and refer themselves to the mental health team if they so wish.*

In addition, some participants agreed that having a CPN and child and adolescent mental health specialist at the surgery would improve access compared to making referrals to mental health services (Focus group 3). However, a different view was put forward by GP1 who described how the low uptake of services resulted in insufficient referrals to CAMHs staff at his practice. GP3 was also concerned about the 'did not attend' rate for young people attending a talking therapy service in the practice.

### ***Basic theme: justified spending***

It was noted that each practice was offered different levels of funding which affected their ability to offer talking therapies. GP2 was particularly concerned that increased spending on talking therapies would not be cost effective due to the common high 'did not attend' rate. GP1 and GP2 strongly felt that practices would be unwilling to initiate a young person's mental health service if it resulted in financial strain on the practice.

#### **Interview 2**

*GP: No mental health is not, not part of it, it is too complicated it is too complicated. You can ask the GPs to solve lots of things not that no ok. You know if we save money on something else we could use it for that but were not going to do you know that's not going to be the way it is that it works if it is already been commissioned elsewhere.*

### ***Basic theme: practice-based commissioning as unsupportive***

The introduction of practice based commissioning was recognised as an important change to primary care provision. One GP participant suggested that practice-based commissioning might cause divergence in provision of young people's mental health services (Focus group 1). Another GP participant believed that a neighbourhood-based commissioning model would require PCPs to agree on providing mental health services for young people in order to implement the quality indicators (Focus group 3). Participants were unsure how practice-based commissioning would actually be implemented and thought that mental health services will be outside practice-based commissioning. GP 1 strongly believed that practice-based commissioning could create further financial issues for practices wanting to provide mental health services for young people:

#### **Interview 1**

*GP: But what practices want to do taking over a commissioning role is create savings which pay the management costs. So I think lots of practices are thinking oh great you know we'll be able to improve services because we'll be in charge. But in fact I don't think they're going to find they can because they might be able to improve things in you know a few areas but in a in a under a currently under resourced area like this anything you do is going to take greater costs and those costs will fall on the practice. So I just can't see how it's going to help and to me it's likely to be worse.*

## **Further suggestions for improving the quality indicators**

Participants made specific suggestions on how they thought the quality indicators could be improved. Changes were suggested in the following areas: presentation; resources; additions and involving other professionals.

### ***Presentation***

Some participants felt that some of the quality indicators could be combined which would reduce the number to be presented to PCPs (Focus group 3 and 4). It was suggested that the term 'should' be replaced with 'would' or 'could'. GP3 suggested that the quality indicators should be rephrased in a more positive way e.g. 'young people have said that they don't mind being asked about personal relationships' (quality indicator 15). One GP participant believed that discussing other treatment options before prescribing medication (quality indicator 6) could be emphasized with stronger wording (Focus group 1).

### ***Resources***

Participants agreed that it was important to include posters and leaflets with the quality indicators and develop an up-to-date directory with Internet resources for PCPs to refer to when consulting with young people (all focus groups and interviews).

### ***Importance of web-based resources***

Some participants felt that web-based information was an important resource for PCPs. It was suggested that a web link to the guidance about how to help a young person with mental health problems would be useful in consultation and help the implementation of changes. Online continuing professional education that practitioners can access easily was noted as a valuable source of training.

### **Interview 2**

*GP: You know so that I think that it would and I'm a great one for you know particularly through choose and book and everything and computers you know what we know is some sort of web-based resource. So you can go to one place which is up so you don't have to keep a folder and take out the odd piece of paper and put the new piece of paper in.*

### ***Additions***

Some participants felt that better definition of 'mental health training' was required. A majority of participants in focus group 1 felt it was important to add the following two provisos to the quality indicators:

1) A PCP may have to tell another person when they are concerned about the young person's welfare and safety when discussing confidentiality (quality indicator 14).

2) Everyone should still be treated as an individual.

One practice counsellor felt it was important to offer alternative ways of getting help for a young person if they are not satisfied with the consultation and have not adequately had their needs met in (Focus group 2). GP3 questioned the extent to which the quality indicators were based on evidence.

***Involving other professionals***

GP 1 felt it was important to send a draft of the quality indicators to the PCT to enable them to incorporate them alongside existing mental health initiatives.

### ***Comparisons between young people's views on help seeking and PCP perspectives of the quality indicators***

The thematic networks resulting from the analysis of young people's views on help seeking and the PCP views of the quality indicators were compared. Each basic, organising and global theme was scrutinised for areas of agreement and disagreement between the data sets in order to identify similarities and differences<sup>22</sup>.

#### ***Similarities between the data sets***

Both young people and PCPs acknowledged that primary care was not the only place to get support for youth mental health problems. PCPs indicated that other sectors were also responsible such as services provided in schools and higher education. Young people also referred to a wide range of services other than primary care that they felt were helpful such as drop in centres and phone lines.

Young people and PCPs had mixed views on the ability of PCPs to meet the needs of young people with mental health problems. Some young people felt that PCPs were useful (organising theme – GPs and counselling as useful) whilst others were less positive about the ability of PCP's to provide support (organising theme - GPs are inappropriate). Data from the focus groups and interviews with PCPs illustrated that they also had a range of views about their ability to manage young people with mental health problems (organising theme – confidence is inconsistent). Some PCPs felt they were ill-equipped to diagnose a mental health problem or prescribe medication whilst others were more confident about how to manage a young person with mental health problems. In addition, both young people and PCPs agreed that there was a lack of time available for consultations about mental health problems.

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<sup>22</sup> It is important to note that although some similarities and differences were identified between the data sets, the two sets of participants were asked different questions. Young people were asked about seeking help for a mental health problem and for their views on the role of PCPs regarding this issue. PCPs were asked for their views on the quality indicators developed by young service users.

### ***Differences between the data sets***

Two sets of themes illustrated the difference in perspectives between young people and PCPs.

Young people were concerned that GPs would not be confidential. However when PCPs discussed the issue of confidentiality (QI 13) a different perspective was indicated. PCPs found it difficult to negotiate confidentiality with a young person because of the need to inform someone else if they felt the young person may harm themselves or others.

Young people felt that it was important to feel comfortable with PCPs when seeking help. However PCPs felt that young people were often difficult to engage as they themselves were not comfortable with managing a consultation with a young person. This was due to both a lack of confidence regarding mental health problems and in some cases difficulty developing a rapport with a young person.

PCPs identified a number of issues regarding the quality indicators. They questioned the validity of the quality indicators because they were implicit in practice (QI 5, 13), difficult to achieve (QI 3 and 4), and led PCPs to consider competing priorities between mental health other health problems managed in primary care. In particular, they disagreed with one quality indicator (QI 9). PCPs felt that they should not be responsible for keeping a young person up to date with their appointment (QI 9).

### **Summary of results**

#### *Young peoples' views of seeking help for mental health problems*

A thematic analysis of the focus groups and interviews with young people led to the development of three global themes. Firstly, not seeking help was interpreted as an appropriate course of action because of the importance of being autonomous, young people did not think or want to admit that they had a problem, GPs were inappropriate, counselling was problematic, and young people lacked knowledge about symptoms and services. However, help seeking was also considered to serve a purpose. This was supported by the concepts that 'self-reliance was not enough', 'GP and counselling was useful', 'personal relationships as first aid' and 'lay knowledge is diverse'. Help seeking was aided by feeling able to feeling able to approach a service or person for help. Finally, help seeking was associated with risk. Young people felt that a lack of confidentiality, fear of negative consequences and a threat to personal relationships would have to be negotiated as a result of seeking help.



### *Development of the quality indicators*

The pilot work showed that it was feasible to include young people with and without mental health problems in the same focus group and discuss a sensitive topic such as seeking help for mental health problems. The focus groups with young homeless people from a night shelter led me to conclude that it would be more appropriate to sample young people living in a hostel with less complex service needs. The pilot focus groups and interviews prompted me to adopt the terms used by young people to describe distress, ask participants to give examples of their experiences and employ the second focus group as way to check and feedback interpretations to the group.

An initial thematic analysis of the focus group and interview data yielded 13 codes from which 49 quality indicators were developed by participatory research groups. These were piloted by a youth expert panel who felt that three should be removed and made amendments to 25 others. Sixteen quality indicators met the criteria for agreement. They illustrate the following areas of quality care: advertising and information; PCP training in mental health and wider range of services and treatment; alternative treatment options before prescribing medication and improved access to talking therapies; information and support regarding the referral process; an explicit confidentiality policy and improved interaction during the consultation.

### *PCP views of the quality indicators*

Thematic analysis of the focus groups and interviews with PCPs led to three global themes. Firstly, PCPs felt that the accountability of primary needed to be established in order to implement the quality indicators. PCPs questioned the validity of some of the quality indicators because of difficulties with communication and providing information, competing interests and the implicit nature of the quality indicators. Discussion about the quality indicators led PCPs to acknowledge the role of other services. PCPs felt that other sectors also had responsibility for youth mental health, debated whether it was a specialist or generalist area and noted the changing interface with mental health teams. Secondly, implementation of the quality indicators would require PCP skills to be examined. Young people with mental health problems were considered a challenging group to manage and confidence in doing so was inconsistent. Finally, PCPs noted that implementation of the quality indicators would need to be supported through commissioning, incentives and clinical guidance at both the practice, regional and national levels.

## **CHAPTER FIVE: DISCUSSION**

This chapter discusses the aims, methods and results within the context of existing literature. I will also outline implications of findings with a view to defining the contribution that this thesis makes to the field of primary care mental health research.

### **Thesis aims**

This thesis has three aims within the over-arching objective of involving young service users in the research process as co-researchers:

- to investigate young people's views on seeking help for mental health problems.
- to develop a set of quality indicators for managing youth mental health problems in primary care.
- to understand practitioners' views of the patient-developed quality indicators.

### **Methodological objective: Involving young service users as co-researchers**

In this study thirty young people were recruited and trained to take part as focus group co-facilitators, assist in data analysis and participate as members of an expert panel. Involving service users in health services research has been strongly promoted by the Department of Health over the last 15 years and is a continuing feature of recent policy recommendations (Department of Health, 2010). As will be discussed in more detail throughout this chapter, this thesis provides evidence that involving young service users in primary care research is feasible and can form part of a rigorous methodological approach to quality improvement. However, there were a number of difficulties that arose throughout the project.

In particular it was important to address ethical concerns regarding confidentiality and to try to anticipate the risks that may be felt by young people taking part in the project (McLaughlin 2005). To this end I conducted a considerable amount of fieldwork which involved contacting and meeting young people and gaining their agreement to participate. The process of engaging young people with experience of mental health problems was a lengthy process that required sensitivity and patience. Training them to be comfortable in their role as focus group co-facilitators meant that I had to make a quick assessment of what skills they were bringing to the research project, and what they needed to improve upon. These activities went considerably beyond what is usually required for research projects that only collect data from participants.

Asking young people to co-facilitate focus groups and interpret data represented for the most part a totally new role that they would not have undertaken previously. This meant that I needed judge how much new information they could effectively take in, and develop methods of group work that would keep them interested (e.g. ice breaker and group cohesion exercises). In a recent participatory research project with young people, Percy-Smith (2007) underestimated the amount of resources required to equip young people with the basic skills and confidence to take part as co-researchers only providing a single training session conducted by the lead researcher with subsequent training sessions being conducted by staff with less research experience. In this study I conducted the two training sessions (co-facilitated by senior researchers) all of which required a significant investment in terms of time and effort as noted by Boutilier and Mason (1997).

Treating participants as researchers challenges the existing social and power relations of research (Oliver 1992; Zarb 1992). This requires researchers to be self aware and critical of obstacles affecting their ability to undertake a truly participative research endeavour (Gibbon 2002). From a professional perspective, I found it difficult to let go and share control of the research process with young people who had relatively less research training, partly because this was my own PhD project with the associated strong feelings of ownership and personal connection to the work.

These experiences illustrate an important concern associated with participatory research. Whilst the aim is to eradicate power differences between researchers and the 'community', actually achieving this in practice is difficult to do (Mason & Boutilier 1996). By resisting sharing power with the young service users I was affecting their level of control over the interpretation of the data. I overcame this conflict by reading more about PR and discussing it with my supervisors. I discovered that it was only by incorporating young people's views and opinions that I was able to maintain the integrity of the methodological approach and hence of the overall project. My commitment to the theoretical assumptions of this thesis – that patients can also be researchers – reaffirmed my understanding of the need to reduce the differences between myself and the participants. This also meant that I could explore my role as a patient and how this impacted upon me as a researcher (See box 5 below). Similarly I was able to become more open to the prospect of sharing power with patients who were learning how to be researchers.

### **Box 5 - Personal reflections**

Having gone through seven years of part-time study on this project I have developed both as a researcher and as an individual. I have learned the value of applying my own experiences to my research. This has made me into a researcher that is more aware of the impact I have on participants and on the way that data is collected and interpreted. Hearing the experiences of other young people has made me appreciate the different ways that people both recover from and manage ongoing problems in their lives. During the study there were times when I found it difficult to disclose my experiences because I was going through therapy at the time of the focus groups. This was a difficult time for me because it was part of the project methodology to share experiences with participants and co-researchers. I had to find a way to comfortably talk about my experiences and one approach that I found helpful was to speak to young people one-on-one rather than to a group. By overcoming this challenge, I learned to reconcile personal issues with the demands of work and study. However, I also discovered that this had a positive effect in that it motivated me to want to speak to other young people more about their experiences and overall I believe this led to me asking questions and interpreting the data differently. Recruiting the co-researchers and participants also allowed me a window into their worlds that added to my fieldwork. Going to their homes, meeting their friends and their children and visiting their schools enabled me to see their lives outside of the research encounter. This added to my interpretations of the data and the writing of the project as a whole. Sharing personal experiences bonded me to the participants in a way that has not taken place with the research projects that I had done in the past and ultimately I believe that this level of reflexivity associated with participatory research led to a more rigorous qualitative methodology.

## **Outcomes of Participatory Research**

Commentators argue that one of the outcomes of using PR is to generate some type of social change either within the research team, the participants (young people and practitioners), or the planned audience (Koch and Kralik 2006). This may include the primary care academic community, young people, parents, commissioners, managers, and practitioners and it is hoped that this thesis will generate debate amongst all these groups about the extent to which the views of patients can have an impact on practice. This has been achieved so far through interacting with the participants and co-researchers through focus groups with practitioners and young people and participatory research meetings. In addition I feel that I have developed both personally and as a researcher (see box above).

Changes in the way patients and practitioners interact with each other is difficult to measure. Some argue that it is not desirable to judge PR in terms of the magnitude of such change (Koch and Kralik 2006) because the focus should be on ongoing learning, but I would argue that for health services research it is important to focus on an identifiable outcome. The outcomes of this thesis differ from that of other PR projects with young people in healthcare that have used art (Percy-Smith 2007) and drama (Jackson 2003) to depict young people's views of healthcare to primary care practitioners. These projects aimed to promote social learning between young people and practitioners whereas this participatory research project aimed to develop a set of quality indicators, to investigate practitioners views about the patient-developed quality indicators and to understand young people's views on seeking help for mental health problems. Although this project may also have led to some form of social learning between young service users and professionals the aim was also to produce a set of tangible results in the form of quality indicators which can be implemented in general practice. The development of the quality indicators will be discussed in more detail later on in this chapter.

## **Young people's views on seeking help for mental health problems and the role of primary care**

The thematic analysis resulted in the following three themes: 'not seeking help is appropriate', 'help seeking is a risk' and 'help seeking is functional'. To the best of my knowledge, and as previously stated, young people's views and experiences about seeking help for mental health problems from primary care has not been investigated using a participatory research model.

### **Global theme: Not seeking help is appropriate**

Using my own experiences and those of the other co-researchers enabled me to take a critical view of the help-seeking process. We concluded that the act of seeking help is one of many aspects of a young person's journey towards improving their mental health. This led to the interpretation of the basic themes into higher themes. So not to seek help isn't necessarily to be interpreted as a 'problem', but it should instead be acknowledged as a reason why young people are less likely to seek help from primary care for their mental health problems compared to other age groups. This approach represents a fundamental difference between this thesis and other studies which take the position that help seeking is the ultimate aim for a young person with mental health problems.

### ***Comparisons with existing literature***

The finding that it is important to cope alone has been previously reported in suicidal youth (Coggan et al. 2001), as well as survey studies with young people (Wilson et al. 2005). Survey studies also show that adults do not seek help because they felt that they could handle the episode themselves (Blumenthal & Endicott 1998). This thesis found that 'the importance of being autonomous' was strongly supported by the Hostel group. Homeless young people have been found to value self-reliance due to issues of rejection and abandonment and are subsequently reluctant to seek help for their mental health problems (Collins & Barker 2009). This may explain why autonomy was a significant factor for this group.

The finding that young people want to cope alone contrasts with Kessler and colleagues (2001) who found that younger subjects (16-34) were less likely than older adults (over 35) to claim autonomy as a reason for not seeking help. They found that young people were more likely to claim that they did not think it was necessary to contact a doctor compared to older adults. This illustrates the methodological differences between quantitative and qualitative data. Survey studies collecting quantitative data report the frequency with which

participants give reasons for seeking help. Although autonomy may have been reported by young participants, they did not report autonomy as frequently as older participants. In the analysis presented in this thesis themes were not only identified by the frequency with which they featured in the data but they were also developed if they featured in more than two data sets and/or had a majority or full group agreement or sensitive moments. So, although a measure of frequency contributed to the development of a theme, other factors were also given value.

Youth help seeking is predicted by a young person's willingness to disclose (Rickwood & Braithwaite 1994) and is more likely when they believe that physicians are effective (Marcell et al. 2005). The findings from this thesis may provide an explanation for these concepts. Young people felt that they would not seek help because of the difficulty in admitting that they have a problem which would make disclosure less likely. Some participants did not believe that health services would be able to help which may explain why a particular provider would be seen as ineffective, and therefore not consulted. In addition, some young people felt they were 'making a fuss about nothing'. This adds to our understanding about how young people assess the 'doctorability' of their symptoms (Heritage 2009). If not seeking help is considered to be appropriate then it may be that a young person does not feel that seeing a PCP is a legitimate course of action. In this way their candidacy for seeking help is affected as they may not feel that they are eligible (Dixon-Woods. et al 2006). The notion of recursivity (Rogers et al. 1999) is also represented by these themes as previous experiences, cultural norms and interactions with professionals contribute to a young person's decision not to seek help.

Many of the basic themes about the negative aspects of seeking help and the role of primary care found in this study have been reported previously. Young people trivialise their mental health problems (Biddle et al. 2006) and consider GPs to lack knowledge (Leon 1999) and be dismissive of mental health problems (Buston 2002). Biddle and colleagues' (2006) qualitative study of young people's views of seeking help from a GP for mental health problems found that they were concerned about the lack of time available for consultation and associated the GP with physical health problems. Studies have also shown that adults trivialise their mental health problems (Gask, et al. 2003; Kadam et al. 2001; Rogers et al. 2001; Pill et al. 2001), are concerned about the lack of time with GPs (Pill et al. 2001), and have limited expectations of primary care (Rogers et al. 2001).

As discussed above, this thesis supports the findings of much of the literature with respect to both youth and adult help-seeking, but also presents a more detailed picture. Previous studies have not specifically reported upon differences between cultural groups within their samples. The findings from this thesis show that negative aspects of the GP experience, although discussed by most of the groups, were especially prominent for young Asian

females. Young Asian women agreed that they perceived GPs to be unhelpful and that GPs were for physical health problems, not issues of mental health. This group was also concerned about being referred by their GP as referrals were associated with travelling far from home which would mean informing their parents. Asian females were also particularly concerned with GP confidentiality. This suggests that ethnicity has an impact upon help seeking for those with mental health problems.

Young people were recruited from a number of different pathways which encompassed those who were using services and those who were not. By contrast, many previous studies simply recruited through services and relied only on professionals for the initial approach to young people to become participants (Buston 2002; Smith 2001).

The finding that young people lack knowledge about mental health problems and sources of help (Wright, et al. 2005; Chew-Graham et al. 2003; Coggan et al. 2001) has been previously reported to affect help seeking for mental health problems. However, specific to this study is the finding that young people have negative views about being referred by their GP and are concerned that counselling lacks meaningful interaction as well as questioning the regulation and qualifications of counsellors.

In addition to Asian females' negative views on referrals, sixth form males perceived receiving a referral as feeling like being dismissed by the GP. This differs from Biddle and colleagues' (2006) study where they reported young people as valuing being referred, and did not report any negative views about GP referrals.

It has been stated that the perceived usefulness of talking to a counsellor predicts the likelihood of a young person seeking help (Vogel & Wester, 2003). This study's findings offer a different explanation in that it may inform our understanding of why counselling may not be considered useful.

This thesis also found that although the lack of meaningful interaction with counsellors was discussed by four of the seven groups, the male groups, (particularly the Black male group) strongly supported this theme. In addition, by not employing pre-defined measures such as those in the attitudes scales used by Vogel and Wester (2003), this thematic analysis broadens our understanding of what factors young people consider to be useful during counselling.

Counselling has frequently been reported as the preferred alternative to family doctors and mental health specialists by young people. It is important to note that this study also found that young people felt that counselling was positive (see following section on help seeking as functional).



Many of the basic themes resulting from the analysis are supported by existing studies although the higher interpretive themes differ from the literature. This may be because I used my own experiences and those of others to ask questions and interpret the data which represents a fundamental difference in methodological approach between this thesis and the existing evidence base. For example, Biddle and colleagues suggest that non-help seeking is due to a 'cycle of avoidance' (Biddle et al. 2007). The findings from the analysis showed that young people described GPs as inappropriate, counselling as problematic, strongly advocated that they wanted to remain autonomous, and noted that young people lack knowledge. By contrast the global theme 'not seeking help is appropriate' was guided by my own experiences and those discussed during the analysis meeting with co-researchers, and illustrates that not seeking help may be a chosen strategy and not 'avoidance'.

## **Help seeking as functional: Comparisons with existing literature**

That young people approach health services when in crisis has been reported for general health problems (Booth et al. 2004), but not for mental health problems. However the concept of being in a 'crisis' is related to symptom severity and there is consensus in the literature that severity of the symptoms of those with a mental health problem is a significant predictor of help seeking (Mauhofer et al. 2009; Biddle et al. 2004). The results from this thesis support this consensus but also show that other factors are important. Some young people felt it was undesirable to cope alone and valued talking to someone who was objective which, to the best of my knowledge, these concepts have not been previously reported as a function of help seeking for young people. This also adds to our understanding of what young people consider to be eligible reasons for seeking help (Heritage 2009).

Positive experiences with GPs, positive attitudes to receiving medication from GPs and being referred by GPs for managing youth mental health problems have all been previously reported by qualitative studies on youth mental health (Biddle, et al. 2006; Leon 1999) and general youth health care (Booth et al. 2004). The results from this study provide a new understanding of why young people consider GPs to be useful at the same time as revealing that some young people accepted that there were constraints placed upon the GP role, and understood that referrals were a necessary part of that role. Specific to this study is the finding that the level of support for the role of GPs and counsellors differed by group. That GPs and counsellors were useful was strongly supported by the Employed group while Black males and sixth form females felt that counselling was beneficial.

That peer groups and family are the primary source of help for young people experiencing mental health problems has been well documented in the literature for young people (Biddle et al. 2006; Secker et al. 1999) and adults (Riedel-Heller et al. 2005). However, the findings from this thesis suggest that this does not apply to all groups of young people as young people living in a hostel did not consider personal relationships to be an appropriate source of support. This suggests that this group may have even less support available to them than other young people. These findings support the notion, as discussed in the previous section, that young homeless people rely on being self-sufficient.

Teachers and other educational professionals have also previously been reported as a source of help (Burns & Rapee, 2006; Wilson et al. 2005; Biddle et al. 2004), although data on the appropriateness of teachers is inconsistent, having also been reported as the lowest preferred source of help (Boldero & Fallon 1995). School counsellors and other types of counsellors are also considered appropriate sources of help for mental health problems (Burns & Rapee 2006). However, as the term 'counselling' is open to a wide interpretation it

is often difficult to determine what type of service 'counselling' refers to. Differences in the meaning of the term 'counselling' was also found in the focus groups discussions and interviews in this study and in comparing the results found here to other studies that have investigated young people's views on counselling, an appreciation that there may be differences in the type of counselling methods and definitions is necessary.

## **Help seeking as risk: Comparisons with existing literature**

The finding that young people were concerned about stigma is supported by Chew-Graham and colleagues' qualitative study which found that medical students avoided seeking help for stress due to the stigma attached to mental health problems (Chew-Graham et al. 2003). Stigma impacts negatively on seeking help for mental health problems in young people (Komiya et al. 2000), and young peoples' concerns about feeling embarrassed to seek help for mental health problems have also been previously reported (Van Voorhees et al. 2005; Van Voorhees et al. 2006). Perceived stigma from friends and family has also been reported as a barrier to seeking help from informal sources for adults (Barney et al. 2009).

Chandra and Minkovitz's (2007) qualitative study with students found that parents may be upset by and not accepting of help-seeking by their child for a mental health problem. Specific to this thesis study, however, is the finding that young female groups in particular felt that parents would not understand, whilst having a high level of expectation for their children which would in turn act to inhibit the young person from discussing their problems with their parents.

Chandra and Minkovitz (2007) found that 8<sup>th</sup> grade boys were reluctant to have conversations with their peers about their mental health. This accords with the results in this study which show that young male groups felt that their male peers would be dismissive of their feelings. But Chandra and Minkovitz also found that young people were concerned that their peers would avoid or tease someone that had sought help for a mental health problem. This is similar, but not identical to the findings of this study that young people are concerned that peers can be unhelpful because of failure to respect confidentiality, acting immaturely, or not being interested. These results illustrate aspects of personal relationships other than those associated with stigma which can explain the negative responses experienced and anticipated by young people.

As previously stated the finding that young people are concerned about confidentiality has been well documented for both mental health problems (Chew-Graham et al. 2003) and general health problems (Booth et al. 2004; Donovan, et al, 1997). However, the findings from this thesis show that the issue of confidentiality was especially marked for young Asian females. Chew-Graham and colleagues (2002) also found that Asian females (including those aged 16-33) felt there was a lack of trust for white GPs because they did not understand the cultural expectations placed upon Asian women, but they were in addition particularly concerned about the confidentiality of Asian GPs, so neither white nor Asian GPs stimulated trust. Asian women were also concerned about negative

consequences of others finding out through through the community grapevine that they had sought help.

Biddle and colleagues found that that young people were concerned about taking medication (Biddle et al. 2006) while negative views about medication have also been reported for young people (Wright et al. 2005). This is compatible with the findings of the present research. However this theme is not unique to young people as studies have also reported that adults are wary about the side effects of medication (Paykel et al. 1998), that medication is the least popular choice of treatment for depression (Riedel-Heller et al. 2005), and that medication is considered to be addictive (Priest et al. 1996).

## **Contrasting results: implications for policy and practice**

There were a number of contrasting themes across the thematic networks which have been interpreted in the following way.

### ***Definitions of mental health literacy***

Participants displayed a diverse knowledge of mental health problems through their own experiences and those of others they knew. They also noted a wide range of sources of help for mental health problems but the concern was also widely expressed that young people lack knowledge about symptoms and sources of help. This contrast between young people's lack of knowledge and diversity of knowledge may stem from the different ways in which the data was generated. The theme 'lack of knowledge' was generated by asking participants about their own experiences and barriers to help seeking. When asked to respond to the vignette, participants displayed a wide knowledge of both mental health problems and sources of help. It may be that there is a difference between responding to a hypothetical situation and what one would actually do for oneself in the real world (Raviv et al. 2000). This may be to any number of reasons, for example the perceived importance of being autonomous.

The contrast between the themes 'lack of knowledge' and 'diversity of knowledge' may also indicate that the knowledge that young people have about mental health problems is incompatible with the language used by practitioners, other service providers and commissioners to describe and recognise mental health problems. The literature has shown that there is a considerable difference between the 'mental health literacy' of young people and adults (Hickie et al. 2007; Burns & Rapee, 2006). Mental health literacy as it is currently defined, assumes the dominant knowledge of practitioners (Jorm, 2000). Rather than claiming that it is young people that need to improve their mental health literacy (Burns & Rapee, 2006), it could be argued that practitioners need to better understand the mental health literacy of young people. If practitioners want to engage young people they need to speak their language. Recognising that there is more than one mental health literacy may facilitate communication between practitioners and young people, but requires practitioners to recognise not only that good communication is a vital necessity of diagnosis and care, but to facilitate that communication they need to learn the literacy of young people, not necessarily the other way round.

### ***Primary care may be suited to some young people and not others***

The findings showed that young people both considered GPs to be inappropriate and reported positive experiences with their GP. These participants were accepting of the limitations of a GPs role in dealing with mental health problems, suggesting that primary care may be suited to those young people who are relatively well informed and willing to disclose their symptoms in a concise manner. The conclusion therefore is that primary care may be an appropriate option for one young person but not another.

That some young people are critical of referrals may result in them not making the effort required to attend or make another appointment. This has important implications for maintaining engagement so that help seeking is useful and meets the needs of a young person. It is important to note that referrals were also considered necessary and were accepted as a normal part of general practice. It may be that some young people are less concerned about travelling to a different service or meeting another health professional and disclosing their experiences and may therefore be more suited to receiving a referral than others. Often the same participants that were supportive of counselling were also critical of the methods used in counselling. Most of these participants had experience of counselling which may indicate that although the processes involved in counselling may be difficult, the overall outcomes of taking part in counselling are beneficial.

The themes 'importance of autonomy', 'fear of negative consequences' and 'lack of confidentiality' contrast with the concept that young people advocate help seeking, illustrating that seeking help may occur when a young person experiencing symptoms has overcome their fears and tendency to rely upon themselves alone.

### ***Informal sources of help***

The results indicated that personal relationships were at once both supportive and problematic. The existing literature shows that family and friends are preferred sources of help and it could be that the risk of seeking help from a family member or a peer are less than the equivalent risks associated with seeking help from medical services. This may be why social networks are considered such important sources of help for young people but in this study the results also show that informal sources of help seeking can be considered to present a risk in their own right, and it is not just formal sources of help that are perceived as risky as is often argued in the literature.

## **Not seeking help is appropriate: Implications for practice and policy**

The finding that non help seeking might be appropriate behaviour has significant implications for practice. Apart from illustrating that in certain circumstances some young people may not want to seek help at all thus making primary care redundant, the results of this study show that to some young people it is entirely rational either not to seek help at all, or if they get so far as to be in consultation with a health professional they still may not want to disclose symptoms or consider their symptoms worthy of discussion. Since help seeking for young people with mental health problems is associated with a willingness to disclose (Rickwood & Braithwaite 1994; Komiya et al. 2000), if instead they normalise their symptoms this can justify their decision not to bring them up in the consultation with a GP or a counsellor. Normalisation of symptoms affects the way adult patients present during consultation (Robbins & Kirmayer 1991) and it is known that adult patients with a normalising style, a common phenomenon in primary care, are less likely to have their mental health problems detected (Kessler et al. 1999). Martinez and colleagues (2006) found that adolescents' perception of their difficulties, and whether this was discussed in the consultation, determined whether psychological problems were detected by GPs. Just as with adults therefore, if a young person is not able to talk about his or her feelings and symptoms openly they are unlikely to seek help or have their problems recognised. Young people may also think that the context of the consultation (such as lack of time or focus on physical health) is not conducive to discussing mental health issues.

Making someone feel comfortable enough to disclose their problems is a skill. It may be that adults that have already developed a close and trusting relationship with young people, such as youth workers, should receive more support with skills and liaison supervision in order to refer on or support young people or encourage them to disclose to others. Professionals with a pastoral role in education could also perform this role. For example school nurses have been found to value mental health work with young people but require supervision and training (Prymachuck et al. 2011).

If a young person eventually does seek help it is important to consider that they may have deliberated for some time about whether it was the right thing to do. They may also have tried other sources of informal help before approaching a health professional help and if practitioners are able to show that they are aware of the history preceding help-seeking, together with the significance of help seeking for the young person, this may enable a young person to be more open during a consultation. This could facilitate disclosure of symptoms which would in turn aid recognition. There were also challenges to the notion of dealing with mental health problems on your own. This will be discussed in the following section.



## **Help seeking as functional: Implications for practice and policy**

Participants strongly advocated that young people should involve another person in their treatment. The moment of recognition that one should not rely entirely upon oneself anymore is a defining one for a young person. It is the point at which it becomes apparent that they need to obtain support and as such it is crucial to the process of help seeking. Participants also felt that it was beneficial to speak to someone that one did not know. It may be that having an objective view of a problem is better than getting advice from people in one's social network. The implication of these findings is that in spite of their being rational explanations for non help seeking, there is a point at which young people acknowledge their need to reach out for help.

Some young people considered GPs and counsellors to be useful which indicates that primary care does have a role and is able to meet the needs of some young people. However, it may be one of many sources of help that are considered of use by young people with some noting a wide range of other services that played a role in seeking help for mental health problems. Having access to help that was immediate was illustrated by the popularity of drop in services and phone lines such as NHS Direct. In addition, existing non-medical services such as Connexions (services for young people), the use of key workers (from homeless group) and educational services were all considered useful sources of help. These findings imply that health and social services are meeting the needs of young people at one time or another.

Non-medical services are often more successful in engaging young people than statutory services such as a GP surgery. They represent sites that young people already frequent to get their social needs met. There is a potential for these services to also act as a source of help for young people's mental health needs although staff that may be skilled at engaging young people, are often lacking the skills to diagnose or treat mental health problems.

## **Help seeking as risk: Implications for practice and policy**

Concerns about stigma may have a significant effect on whether a young person feels confident enough to disclose personal information to a third party and when it comes to disclosing mental health problems the fear of being stigmatized can be even greater. If a young person has any fear at all that confidentiality may be thrown into question this may discourage them from disclosing any information about their situation. Not wanting to disclose experiences and symptoms may have an impact upon whether or not a problem is recognised. Asian females, and Sixth form males and females were unsure as to whether information shared with GPs would be kept confidential. Participants in these

groups were all aged 16-17 while other focus groups were made up of young people aged 18-24. Sixteen and seventeen year olds may be more concerned about parents finding out information because they are more likely to live with them, and this can be further exacerbated by GPs often knowing and treating the entire family with all the commensurate fears that confidential information might be shared with parents. This may also be more of an issue in the Asian community as parents and GPs often have relationships outside of surgery.

Help seeking may be perceived as a risk because of the effect on a relationship, demonstrating that young people are generally more isolated than previously considered. Not being able to approach others in your social network for support would impede the help seeking process. Both the all male groups (Sixth form males and Black males) felt that their peers would be dismissive about someone's feelings. This may discourage young men from talking about their emotions when experiencing problems and may go some way towards explaining why young men are often the least likely to seek help (Oliver et al. 2005; Biddle, et al. 2004).

If young people think that they will be offered medication by their GP and have concerns about medication, this may act as a further barrier to help seeking. Clinical guidelines state that anti-depressants are not recommended for young people under the age of 18 and for individuals aged over 18 they are only recommended in combination with talking therapies for moderate and severe depression (NICE 2005). However, medication is often the only immediate treatment option that PCPs can offer a young person due to the low availability of talking therapies. The provision of talking therapies should be improved with the new IAPT initiative which may reduce practitioners' reliance on prescribing anti-depressants but for the moment the impression that many young people have that they will simply be offered medication for their mental health problems is quite well founded.

### **Strengths of the study**

Using a participatory methodology enabled an examination of the role of primary care and help seeking from the young person's perspective. Initial themes were fed back to each focus group to ensure that participants agreed with our interpretations. The interpretation of the data was influenced by my experiences of counselling. Data collection and analysis was conducted with four other researchers and three young service user so each co-researcher will have brought experiences and opinions about seeking help for mental health problems and the role of primary care to the research. We disclosed our experiences to focus group and interview participants which may well have encouraged participants to speak more freely. Studies have shown that patients report being less satisfied with

services when they are interviewed by other users of the service (Clark et al. 1999; Polowczyk et al. 1993) possibly because researchers with experience of mental health problems may ask different questions and develop alternative interpretations of the data (Rose et al. 2006). This approach may deliver results that are more closely associated with the perspectives of young people experiencing mental health problems than of studies not adopting such methods.

Much of the help seeking literature on young adults is based on samples of college students. This study purposely selected young adults that were both in education and those that were in the more vulnerable positions of being unemployed, at risk of using substances, and being homeless. Although other groups, for example young refugees and asylum seekers, are known to be at risk of developing mental health problems, these were not explicitly included in the sample. A significant number of participants in the homeless and African-Caribbean male groups were unemployed and the African-Caribbean male group was held at a drop in centre that advises young people with substance use problems.

One of the aims of this study was to understand the views of a mixed community sample of young people who had had some experience of primary care. Therefore, we purposely recruited both young people in education and employment and young people from groups known to be at risk of developing mental health problems. In the study setting of Lambeth, Southwark, Lewisham and Croydon the mean percentage of 16-24 year olds in education is 44% compared to 41% in employment (Office for National Statistics 2001). The sample of young people roughly matched this proportional balance with 57% in education and 43% in employment or other non-educational activities. Overall, the sample was recruited from inner-London PCTs providing results that can be generalised within this setting. It may not be possible to apply these findings to other settings such as rural and sub-urban young adult primary care populations.

This analysis has produced a pattern of contrasting themes which may have resulted from the use of focus groups. Focus groups seek to uncover the way that social norms are produced by providing an insight into the way that individuals develop their thinking about a particular topic through interaction (Kitzinger 1994) so within a group there will be differences of opinion and experiences that are played out through the group discussion. Adopting this methodology may have led to the diverse range of opinions that were found and provided an insight into how those opinions are formulated. This is one of the first studies to have used focus groups with young service users as co-researchers to investigate the views of young people about seeking help for mental health problems and as a result this thesis adds to existing knowledge by contributing new interpretations developed using participatory research methodology with young service users.

## **Study limitations**

Although the entire sample had had some experience of primary care, not all had a history of serious or common mental health problems. However, at least half of the participants in each focus group and all three interviewees had experienced a self-reported mental health problem. The study is therefore limited to providing a framework for help seeking from the perspectives of a mixed group and it cannot claim to apply its findings specifically to young people with mental health problems. There is a general consensus in the literature that severity of symptoms is a reliable predictor of help seeking in both young people and adults. In addition previous experience of seeking help is related to positive attitudes towards seeking psychological help (Halgin et al. 1987). Had the sample therefore only included young people with previous experience of mental health problems and of seeking help the findings may have been more positive regarding the role of primary care. However, most of the themes found in studies that did focus solely on young people with mental health problems, such as those reported by Biddle and colleagues (2006) were complemented by the basic themes generated in this analysis.

Having had my own experiences of counselling may have reduced my ability to challenge shared assumptions during data analysis. However, all researchers bring their experiences and assumptions to bear upon the interpretation of the data. It is important that these are made as transparent as possible through reflexive research practices such as verbal disclosure to the research team, writing about my personal reflections and providing examples of how these impacted upon data analysis through the use of memos that are presented in this thesis. In addition, also having the data coded by researchers in the team without experience of service use ensured that other interpretations were considered and not only my own.

Focus group methodology was chosen because it complemented the involvement of young service users. Therefore one-to-one interviews were not considered appropriate as the young service users would have had to undertake more research training than was planned. The participants in all but one group spoke openly about their views and experiences of seeking help for mental health problems. However, participants in the Asian female group were more guarded than other groups despite informing me they were happy share their experiences before the focus groups took place. This highlights one of the issues with focus group methods. Individuals may not be willing to disclose information to the group. However, this tension was incorporated into the analysis and contributed to the development of the theme 'concerns about approaching close friends and family'. In order to include the experiences of the participants that were not disclosed within the focus group I conducted individual interviews with each participant.

There is a consensus in the literature that help seeking is predicted by gender. In this study, a minority of the focus groups were sampled on the basis of gender (sixth form males and sixth form females) and as a result comparisons on the basis of gender are somewhat tentative. Secondly, the aim of this study was to have young people from different ethnic minority groups together with those that were homeless. These groups were of interest because they have been shown to be vulnerable to mental health problems and have complex pathways to care. The focus groups were however somewhat heterogeneous in terms of ethnicity so extensive comparisons by ethnicity were not possible though some preliminary differences emerged. In retrospect, making the groups more homogenous would have enabled further cross group comparisons.

As discussed in the previous sections, participatory research aims to produce some form of personal growth in those that take part as co-researchers. Informal conversations took place during and after the research meetings, but no data was collected relating to how the young people felt about the process of being involved in the research project. This would have required more time and resources than were available on this project though future research proposals using this methodology should feature interviews with co-researchers to explore their experiences.

## **Development of the patient-generated quality indicators**

Sixteen quality indicators for primary care mental health were developed using participatory research methods with young people who had experience of mental health problems and primary care researchers.

### ***Development of young service user-defined quality indicators: methodological issues***

Nominal Group Technique (NGT) was a successful way of engaging young people in the production of quality indicators. All the participants who started the nominal group completed it, and all participants who were in first group returned for the second group. All of the young service users maintained their focus on the rating activities and completed the task. They contributed equally to open discussion and shared personal experiences with one another. I did not experience the more negative aspects of young service user participation found by Laenen where young people were distrustful of the researcher, partly because she was an adult and a professional (Laenen 2009) although clearly I fitted both those descriptions. This assertion is however based on my own interpretation and not that of the young service users themselves, so it is just possible I may have missed negative signals.

The 24 young service users that took part in the nominal groups were recruited from the community, specialist mental health services, user groups and higher education. Although young service users responded to adverts placed in the recruitment sites, gatekeepers also informed young people about the project. Those taking part were therefore not necessarily representative of all young service users. This concern has been raised by other studies that have involved service users in NGT (Barlow et al 2007).

Building trusting relationships and a sense of ownership of the project is an important aspect of conducting participatory research with young service users. This task is best done with a smaller rather than larger number of participants. In addition, recruiting young service users to take part in a nominal group takes a considerable amount of time and effort. Involving a larger number of participants (and thus improving representativeness) could be achieved using other consensus methods such as the Delphi technique. Using the Delphi method would reduce my own and other service users' ability to interact with each other which I found to be an important factor in the engagement and retention of young vulnerable people leading me to believe that the Delphi method would not have been necessarily helpful.

### ***Similarities with existing quality indicators***

The literature review found six comparable published reports and studies about quality indicators and standards in youth healthcare and primary care (see pages 53-61). These publications and other relevant work will be compared and contrasted with the resulting service user-developed quality indicators from this study. I did not find any other studies which involved young people with mental health problems (as the majority participant group) in the development of quality indicators for primary care.

Four of the quality indicators for primary care mental health developed by Shield and colleagues (2003) are similar to the patient-developed quality indicators from this study.

These are:

- mental health training
- the provision of appropriate information
- equitable access to talking therapies
- an awareness of stigma

However a majority (12/16) of the patient-developed quality indicators from this study did not feature in Shield and colleagues (2003) quality indicators. The patient-developed quality indicators differed from Shield and colleagues' quality indicators in the following aspects of care: referral protocol, modes of treatment and making practice policies explicit. These may represent aspects of primary care mental health that are specific to the needs of young people. Shield and colleagues observed that rankings differed between the 11 different stake-holder groups which were made up of practitioners from primary care, mental health specialists, health and social care commissioners, and patient and carer organizations (Campbell et al. 2004). In this study, however, having a nominal group with only young service users (thereby excluding other stake-holder groups) may have produced quality indicators that were better aligned to the needs of young people with mental health problems. This suggests that the patient-developed quality indicators have face validity.

There are also some similarities between the patient-generated quality indicators and the Royal College of General Practitioners (RCGP) guidelines on how to make practices more 'teenage friendly' (Royal College of Nursing & Royal College of General Practitioners 2002). These include advertising and reassuring young people about confidentiality; training staff about teenage health issues; advertising services available in the practice and offering information about local services. This suggests that advertising services and policies (which include how confidentiality is managed), are important aspects of quality care for young people compared to other age groups.

Quality indicator 2 (practitioners should have mental health training) is strongly supported by other publications. Training was a consistent feature in all six comparison publications. The patient-developed quality indicators which refer to providing information and confidentiality also feature in a majority of the comparison publications. This high level of agreement with other quality improvement initiatives validates the patient-developed quality indicators.

***Differences: what this study adds***

Specific to this study is the finding that patient-developed quality indicators for youth mental health focus on wider treatment options, referral protocol, and interaction during consultation. Three of the sixteen quality indicators from this study refer to the provision of further treatment options. For example, young service users felt it was important that alternatives to medication were discussed; self help options were considered and that access to talking therapies was made easier. These aspects of quality primary care were found in a minority of existing guidance. Only two of the six comparison quality initiatives called for improvements in access to talking therapies. Shield and colleagues (2003) referred to 'equitable access to talking therapies'. The You're Welcome standards stated that 'counselling should be available to young people on site' (Department of Health 2007).

Significantly NICE guidelines support the discussion of alternatives to medication and self-help options by calling for 'a discussion of alternatives when deciding on treatment for the patient' and stating the need to 'encourage self-help group attendance if appropriate' (NICE 2005). That further treatment options are lacking in a majority of the comparison publications may be because they mainly focus on health in general, and not specifically on mental health.

The RCGP guidelines differ from the results of this study in that they recommend that practices also focus on the surgery environment, undertake an audit of young people's views, hold a young person's clinic and involve parents (Royal College of General Practitioners & Royal College of Nursing 2002). The RCGP guidelines were produced by practitioners and therefore may represent aspects of care that practitioners think are important for young people but that young people do not consider important, or they illustrate aspects of care that practitioners think are important irrespective of young people's views. This may explain why they differ from the results of this study. The RCGP guidelines also focus on sexual health and teenage pregnancy but not mental health.

Three of the sixteen quality indicators developed by young patients focused explicitly on referral protocol. These stated that young people should be kept up to date about the progress of their referral; be informed about what to expect, and that waiting times be kept



as short as possible. This aspect of quality care has been found in only one other comparison publication. The CAMHs service standards (Royal College of Psychiatrists 2006) state that 'patients should know what to expect' but is not clear to what extent this was the responsibility of primary care. None of the other quality improvement publications focused on how referrals were made in primary care, either within the practice or to external agencies such as CAMHs.

The patient-developed quality indicators stated that practitioners should be more interactive and ask questions about their social network. For example, young people felt it was important that primary care practitioners should demonstrate their awareness of the potential embarrassment that a young person may feel about admitting their mental illness by giving them reassurance and empathy regarding those feelings. A comparable quality indicator was found in only one other publication. Shield and colleagues' (2003) quality indicator 'practitioners have an awareness that patients may feel stigmatised'.

### **Implications for practice and policy**

Currently, patient surveys are widely used in health services to assess patient views e.g. quality and outcomes framework but there is little evidence to suggest that these have an impact on service development. When it comes specifically to youth, commentators argue that patient surveys have had relatively little impact on service delivery (Worrall-Davies & Marino-Francis 2008). In other healthcare sectors methods of incorporating patient views into practice and service delivery include patient feedback through making videos of experience (e.g. Kings breast cancer clinics), but again the impact, if any, on practice remains largely to be established. Patient-generated quality indicators promote patient views into something more tangible than a set of survey results with the effect that this offers a more formal method of incorporating patient views into policy and commissioning.

The recent NHS White Paper has put an increased focus on the use of quality indicators to measure performance (Department of Health, 2010). However patient and carer involvement in the development of the quality indicators by NICE has been mainly via consultation after they have been generated, rather than beforehand. When patients are involved in the development of quality indicators and in guideline development groups it is not clear how well the issues of power differentials during the meetings are addressed. If group dynamics are not carefully considered patients may not speak openly nor have their concerns taken into consideration (van Wersch & Eccles 2001). This study adopted a participatory approach with the specific intention of reducing the differences in status between the researcher and the participants.

Disclosing shared experiences of help seeking between co-researchers and participants was also encouraged. Involving service users as interviewers and in questionnaire development is a core feature of user research in the mental health field (Rose et al. 2001; 2008). This methodological approach leads to different questions being asked that may be more closely aligned to the needs and experiences of people receiving services (Rose et al. 2008). As this is the first study to involve young service users in the development of quality indicators for primary care mental health it is to be hoped that the quality indicators that resulted might be more sensitive and relevant to the needs of young people.

It has been argued that although patient involvement has a pivotal role in quality assessment it cannot stand on its own as a way of assessing quality of primary care (Elwyn et al. 2007). I partially agree with this viewpoint. Quality indicators will only be incorporated into practice if practitioners feel they have value and are of use. Practitioners need therefore to be consulted and involved in their development. GP academics were involved in data analysis and facilitated the participatory research and nominal group meetings and so, although the quality indicators were *user-focused*, they were also collaborative. Indeed it is important that patient involvement in health service research is a collaborative effort because it is professionals who are being asked to change their attitudes and behaviour. The importance of professionals' perspectives regarding the implementation of the quality indicators was demonstrated in focus groups with professionals regarding their views on the patient-developed quality indicators (see next section). However, practitioners have more power to make an impact upon quality improvement than do patients through their role as commissioners, involvement in ethics committees and as researchers. By using participatory methods this study produced quality indicators that can lead to more patient-centred quality assessments for primary care.

### **Study strengths**

The material used to develop the quality indicators was developed from focus groups and interviews with community samples of young people. Young people with experience of mental health problems co-facilitated the community focus groups and developed and disseminated the quality indicators to practitioners. Practitioners were also involved, but to a lesser degree, in the development of the quality indicators. This meant that the resulting quality indicators were developed with a strong focus on the perspectives of young people rather than that of practitioners.

Although there was no formal evaluation conducted, PCP views of the quality indicators were investigated through focus groups and interviews. This provided an opportunity to examine the systems (e.g. culture, structure, resources and policies) within which the

quality indicators would most likely be implemented. The results are discussed in more detail in the next section.

An inclusive sampling strategy was adopted to ensure that the focus groups, youth expert panels and co-researchers had a wide representation of young people from different socio-economic groups. As well as recruiting from GP practices young people were purposely recruited from CAMHs, housing services, substance use services and an eating disorders website so that young people who did not access help from primary care were also included in the youth expert panel. An effort was also made to recruit young people from a range of ethnicities and occupations.

### **Study limitations**

Being involved in research often has a positive impact upon young people (Powers & Tiffany 2006). This study did not document co-researchers experiences of being involved to assess whether the young people benefitted from taking part. This was mainly because my resources were focussed on achieving the aims of the study: developing patient-generated quality indicators and investigating PCPs views using a participatory research model. Percy-Smith (2007) also reported he was unable to evaluate the impact of the research on participants beyond the research funding period.

I did have numerous conversations with the young people during the course of the study and from an anecdotal perspective I can report that they very much enjoyed taking part in the training meetings, focus groups and nominal groups. The young people said that they valued hearing other people's stories about their experiences of mental health problems and help seeking. The co-researchers that facilitated the focus groups with practitioners mentioned that they felt able to interact with practitioners without 'feeling like a patient'. This indicates that young people felt empowered by being involved as co-researchers.

Participatory research ideally involves lay people in all stages of the research process i.e. developing the research question, data collection, data analysis, dissemination. For this study young people were not involved in developing the research question but they were involved in data collection, interpretation and disseminating the results to practitioners. When recruiting young people to the project I explained to them that they would be involved in a research project which had a predefined research aim as is considered best practice (West 1999). As this thesis is not yet published, young people have not had the opportunity to be involved in dissemination but they did present the quality indicators to practitioners during the focus groups. Further involvement in dissemination would not have been feasible due to the time and funding limitations of the 4-year project. In any future PR project the involvement of lay people in developing the research question and

disseminating the results would be built into the proposal with an adequate time and funding resource so as to elicit co-researchers views on the positive and possibly negative aspects of being involved with the protocol.

Participants that opted into the project may have been young people who had a particular grievance to air. Reasons for agreeing to participate in research vary and having something to say or being interested in the topic is a common reason why people agree take part. The issue of bias is a limitation that affects all studies. But in a PR project it is these very experiences that are of value to the research process. Being motivated to become and remain involved in the research often includes having strong feelings about the research topic. Some young people were recruited through their clinicians who told patients about the project and so their decision who to approach may have introduced selection bias.

Shield and colleagues (2003) define quality indicators as an 'element of practice that can be retrospectively measured'. In order to be measurable a quality indicator needs also to be specific so that an assessment can be made on whether the quality indicator is in place or has occurred. Most of the patient-developed quality indicators could be interpreted in a number of different ways. Because of this they would require further refinement to make them more specific and measurable. In addition, the quality indicators do not distinguish between common and more severe mental health problems. As primary care practitioners manage mild to moderate mental health problems and may refer more severe cases to specialist services this may have an impact upon how useful they are perceived to be by practitioners.

### **Methodological differences between studies**

The differences across the three thematic networks illustrate how qualitative methods can expose the ambiguity of a concept which may not be seen using other methods (Mays & Pope 1995). Methodological differences may also account for the contrasts between the quality indicators and young people's views on help seeking. The quality indicators set out aspects of good quality primary care for young people with mental health problems, and are therefore supportive of help seeking from primary care. The thematic analysis illustrated how help seeking can be problematic for a young person. The quality indicators were developed by asking young people to reach an agreement through nominal group technique. But the thematic analysis was conducted with focus group data, with the young people being encouraged to provide alternative views and opinions about experiences and views of seeking help for mental health problems without the requirement of reaching a consensus on what constitutes quality of care.

## Primary care professionals' views of the quality indicators

PCP views of each indicator are summarised in table 25 and discussed below. The results of the thematic analysis are discussed in the following section.

**Table 25: Summary of PCP views of the quality indicators**

Quality Indicator (QI)	Practice or Patient Level	Summary of PCP Views
1) Primary care practitioners should advertise that they are available to help young people with mental health difficulties.	Practice	Easy to do and is already done in practice. Would be hesitant to do so if access to talking therapies is low.
2) All primary care practitioners should have mental health training.	Practice	Variation in training Needs better definition
3) Primary care practitioners should have up-to-date information about local specialist mental health services.	Practice	Difficult to provide up to date information.
4) Primary care practitioners must have up-to-date information about other local services to give to young people.	Practice	As above
5) Primary care practitioners should discuss other treatment options before prescribing medication to a young person.	Patient	Implicit in practice
6) Young people should be able to see a mental health specialist at the GP surgery.	Practice	Some felt they were meeting this indicator through providing access to a range of services others felt it was not deliverable.
7) Access to talking therapies needs to be made easier as an alternative to medication for mental health problems.	Practice	Desirable but practitioners felt they lacked control over access to talking therapies. Need to justify the costs and benefits of increasing the availability of talking therapies Variation in demand for talking therapies.
8) Referral times for young people should be as short as possible to reduce the stress experienced while waiting for an appointment.	Patient	Some agreed and others felt that this should apply to patients of all ages and not only young people.
9) For referrals within the GP surgery, primary care practitioners should keep the young person up to date with the progress of the appointment.	Patient	PCPs did not think that they should be held accountable for keeping young people up to date with the progress of their appointment.

10) If making a referral, primary care practitioners should provide information for young people about what to expect at the first appointment.	Patient	Some agreed that this should be done and some felt it was already done in practice. One GP felt it was the responsibility of the receiving agency and not the PCP.
11) Primary care practitioners should discuss ways that you can help yourself overcome the symptoms of mental health problems.	Patient	Implicit to practice
12) Counsellors need to be more interactive with young people rather than just listen and write notes.	Patient	Not discussed <sup>23</sup>
13) Primary care practitioners should have a strict confidentiality policy, which they state, at the beginning of the consultation preventing them from disclosing information to members of the young person's family.	Patient	Implicit in practice but some PCPs acknowledged that confidentiality protocols were not always made clear to young people.  Negotiating confidentiality is difficult because it needs to be broken if a young person is a danger to themselves.
14) Primary care practitioners should appreciate that young people can feel embarrassed to seek help and should reassure them that mental health problems are common	Patient	Implicit to practice
15) Primary care practitioners should ask questions about young persons' relationships and support network.	Patient	Implicit to practice
16) An ideal place for help with mental health problems would offer a variety of treatments for young people.	Practice	Not discussed <sup>24</sup>

<sup>23</sup> Quality indicator 12 was not directly discussed during the focus groups. This may be because there were a minority of counsellors in the sample.

<sup>24</sup> Quality indicator 16 was not discussed directly during the focus groups but is related to quality indicators 7, 6, 5, and 11.

***Quality Indicator 1) Primary care practitioners should advertise that they are available to help young people with mental health difficulties.***

PCPs felt this was easy to do and was often already done in practice. Some PCPs noted that they would be hesitant to advertise talking therapies if they were difficult to access. This quality indicator could be implemented using posters and leaflets or other methods of communication with patients such as text messages, emails or message boards in the waiting room. It may be more challenging for practices to ensure that they are able to offer patients the services for which they were advertising (e.g. talking therapies or CBT). Much of the literature about advertising a service reports upon research projects whereby the services that are advertised are funded for a finite period of time. For example, sending an advert for depression support enabled a group of depressed patients to receive help through assessment and case management by nurses and doctors in a GP practice (Symons et al. 2004). Whilst short term research projects indeed add to the evidence base in everyday practice advertising services within primary care would require adequate long term funding and support through commissioning decisions to ensure that those services were indeed available. This is discussed in more detail below (see Q16 and Q17).

Advertising to patients that PCPs are available to help young people with mental health difficulties would also require PCPs to have the skills to support young people with mental health problems who may ask for help after seeing an advertisement. This is discussed in more detail below.

***Quality Indicator 2) All primary care practitioners should have mental health training.***

The findings show that there is wide variation in the amount of training that PCPs receive regarding mental health problems in young people. This may have been due to the recruitment of multi-practitioner focus groups and differences in skill mix within the groups. GPs and practice nurses (PNs) will have received some mental health training as part of their early training although there are differences in what is offered and completed. For example, some will have had a 6-month psychiatry rotation although this is not compulsory or usual. Youth workers practicing in primary care will be skilled in engaging young people in an activity or service and so may not experience the same difficulties as some generalists or mental health specialists who do not specifically work with young people e.g. GPs or counsellors. However, youth workers are likely not to be as skilled in recognising and managing mental health problems as are some generalists and mental health specialists.

Most practitioners work in teams and it may be that one member of the team with a special interest within the group could act as a local champion by generating training opportunities

for others in the primary care team. This type of role would be crucial in implementing this quality indicator. Local champions are often used as a source of knowledge and colleagues may refer young people to a practitioner that has an interest in youth mental health and is confident in dealing with the complexities of mental health problems in young people.

***Quality indicator 3) Primary care practitioners should have up-to-date information about local specialist mental health services.***

***Quality Indicator 4) Primary care practitioners must have up-to-date information about other local services to give to young people.***

PCPs felt it was difficult to provide up to date information about local services. This may be because services often close down or alter their remit due to changes in funding. Practices often rely upon external services to provide information such as leaflets so meeting this quality indicator would rely upon good communication with other agencies and services. Other methods include the sharing of information between practitioners such as local champions and patients who have used a particular service. This could be facilitated at practice meetings or through a patient participation group.

***Quality Indicator 5) Primary care practitioners should discuss other treatment options before prescribing medication to a young person.***

***Quality Indicator 11) Primary care practitioners should discuss ways that you can help yourself overcome the symptoms of mental health problems***

Practitioners felt that discussing other treatment options before prescribing medication was an implicit aspect of their practice. However PCPs do prescribe medication because it is often the only way that they can provide immediate help to a young person with mental health problems. This often happens because of a lack of available talking therapies.

Prescription of medication also depends upon a number of factors. For example, NICE guidelines for depression state that medication should only be offered to those with:

- present or with a history of moderate to severe depression,
- sub-threshold depressive symptoms present for 2 years or more or
- mild depression persisting despite other interventions (NICE 2009).

For young people under 18, psychological therapies are the first line treatment and medication is only offered in conjunction with psychological therapies for those with



moderate or severe depression (NICE 2005). With regard to NICE guidance, implementing quality indicator 5 would thus depend in part upon the presenting symptoms. Therefore a PCP would have to assess whether it was appropriate to discuss other treatment options with a young person on the basis of their symptoms and how they presented in consultation. Both quality indicators 5 and 11 could be implemented using screen prompts. However, the ability to offer other treatment options (such as talking therapies) would rely upon commissioning decisions. This is discussed in more detail below (see QI 6 and 7).

PCPs felt that discussing self help options for managing a mental health problem was also an implicit part of their practice. As with medication treatment discussed above, NICE guidance on depression states that individual and group based self help programmes should be offered for both adults and young people (NICE 2005; 2009). Self-help options are recommended as part of low intensity psychological intervention for those aged 18 and over with persistent sub-threshold depression (and those with a physical condition that complicate the care of this) and mild to moderate depression. For young people it is recommended that self-help is offered for mild depression and is delivered within a primary care setting. This indicates that self help options are considered appropriate in some but not all cases. Someone who has more severe symptoms may benefit more from other types of treatment. These quality indicators that focus on treatment options (QI 5 and QI11) therefore would need to be interpreted within the context of the presenting symptoms and diagnosis.

***Quality Indicator 6) Young people should be able to see a mental health specialist at the GP surgery.***

***Quality Indicator 7) Access to talking therapies needs to be made easier as an alternative to medication for mental health problems.***

Some practitioners from a larger surgery (FG1) felt they were meeting quality indicator 6 by providing access to mental health specialists within the practice whereas others from smaller practices (GP1) did not think it was desirable or deliverable to do so. These divergent views may have been a reflection of the different levels of mental health services offered to practices according to their size. Some PCPs felt that mental health problems should be managed within secondary care which may explain the view that access to specialists within primary care would not be desirable.

PCPs also felt that they lacked control over access to talking therapies. This would therefore affect their ability to offer specialist mental health services (QI6) and improve access to talking therapies (QI7). Practitioner concern about the lack of resources for

referral has been widely reported in the literature for adults (Sigel & Leiper, 2004; Chew-Graham et al. 2002; Rogers et al. 2001), older adults (Burroughs et al. 2006), and young people (Richardson et al. 2007). The findings from this study illustrate the theme in more detail however. PCPs cite the lack of resources for referral as a barrier to managing mental health problems in primary care (Chew-Graham et al. 2002; Rogers et al. 2001) but PCP concern about variation in demand for talking therapies and justified spending as found in this study has not been specifically reported. These are new findings that have not yet been reported in the literature for young people, possibly because PCPs were asked for their views on quality indicators which had been developed by young people. In addition, because these quality indicators represented aspects of care that could potentially be used to assess PCPs, other elements outside of their immediate control were discussed such as factors that affect commissioning decisions. This indicates that quality indicators 6 and 7 should be aimed at practice level and not at individual practitioners.

Quality indicators 6 and 7 could be implemented through the commissioning of specialist mental health services by practices. During the writing of this thesis, IAPT and the new Government White paper on GP commissioning were introduced. As the GP consortia model responsible for commissioning has not yet been launched, and will most likely emerge from existing practice-based commissioning (PBC) clusters (Department of Health, 2010) I will focus my discussion on PBC. Under PBC, the IAPT programme is commissioned on the basis of a needs assessment. As a result young people with mental health problems would need to be identified by commissioners as an important group for the practice to focus resources upon so as to implement the patient-developed quality indicators. Although PBC may give practitioners more control over which services they can provide, thereby reducing their frustration about lack of resources (May et al. 2004), a lack of GP engagement and managerial support has stalled the progress of this model of commissioning (Gillam & Lewis, 2009).

***Quality Indicator 8) Referral times should be as short as possible for young people.***

Some PCPs felt that because young people were difficult to engage it would be important not to lose the momentum once a young person had sought help from primary care. One way of 'holding' a young person would be reduce the amount of time they had to wait between first being seen by a PCP and the service or other professional to which they are referred. However, giving one group of patients priority over others does not promote equitable access. Within primary care there are often different health problems and patient groups that compete for access to services. If this quality indicator were to be met practices would need to make the decision to give priority to young people over other age groups. This could perhaps be justified for practices with a high proportion of young people on the

patient list or if they were the designated practice within a cluster of practices to chosen provide services for young people with mental health problems.

The criteria for referral to specialist services is usually based upon case severity (Kramer and Garralda 2000) and not age. In most cases a young person aged 16-17 would be referred to CAMHs. If aged 18 years and older they would be referred to adult services such as a CMHT. Some CAMHs teams may stretch to 18 if a patient has been using their services previously to enable of continuity of care. Others may be reluctant to take on a patient aged 16 or 17 because their treatment would be likely to continue past the age limit for the service. Implementing this quality indicator would thus be highly dependent upon the availability of other services to which the referral was to be made.

***Quality Indicator 9) For referrals within the GP surgery, primary care practitioners should keep the young person up to date with the progress of the appointment.***

PCPs felt they should not be responsible for keeping a young person up to date with their appointment. However, sending appointment reminders would more likely be carried out by an administrator rather than a PCP. The evidence shows that sending appointment reminders by text message does improve attendance in primary care (Leong et al. 2006) and at adolescent clinics (Sawyer et al. 2002). Therefore as well as an indicator of quality, keeping a young person up to date with their appointment could also improve cost effectiveness as missed appointments may be reduced. Appointment reminders by text and phone message are becoming more common practice in primary care and so should be relatively easy to implement for referrals within the practice. It may be more difficult for primary care practices to inform young people about their appointments with external agencies e.g. CAMHs. Therefore a clear distinction between the two types of referral would improve implementation of this quality indicator.

***Quality Indicator 10) If making a referral, primary care practitioners should provide information for young people about what to expect at the first appointment.***

Most PCPs agreed with this indicator and felt it was already carried out in practice. One PCP disagreed and felt it was the responsibility of the receiving service. Providing patients with appropriate information about their referral is specified as part of a person-centred care is outlined by NICE guidance (NICE 2009, NICE 2005). Providing information about what to expect once referred can depend on the service one is being referred to and how much knowledge the PCP has about that service. Providing information to patients could be implemented in a number of different ways such as discussion in consultation, leaflets and directing patients towards information on the internet.

***Quality Indicator 13) Primary care practitioners should have a strict confidentiality policy, which they state, at the beginning of the consultation preventing them from disclosing information to members of the young person's family.***

PCPs felt that this quality indicator was also implicit in practice but some acknowledged that confidentiality protocols were not always made clear to young people. They also felt that negotiating confidentiality is difficult because it would have to be broken if a young person is a danger to themselves. Fears over confidentiality are one of the most frequently reported barriers to help-seeking from Primary care for young people (Tylee et al. 2007) while young people may be more likely to disclose sensitive information to practitioners who have provided assurance with regard to confidentiality during the consultation (Ford et al. 1997).

The term 'confidential' and 'confidentiality' is commonly used by both young people and PCPs but it may have different meanings for both groups. As such it would be useful to have a clear definition of confidentiality and reasons for why it may be broken. From a PCPs perspective, confidentiality may in fact mean that although a young person may trust a PCP with information about them it does not mean that they will not disclose some or part of that information to another person if the PCP considers the young person to be a danger to themselves or others. On the other hand a young person may consider confidentiality to mean that information disclosed to a PCP will not be shared with anyone else irrespective of whether or not they are judged to be in a dangerous situation. If issues of medical responsibility regarding self harm and harm to others are discussed with young people they may reassured of what confidentiality means during a consultation. This could be implemented using screen prompts and posters.

***Quality Indicator 14) Primary care practitioners should appreciate that young people can feel embarrassed to seek help and should reassure them that mental health problems are common***

***Quality indicator 15) Primary care practitioners should ask questions about young persons' relationships and support network.***

For these quality indicators PCPs did not discuss whether they agreed or disagreed but responded with a clear assurance that they were an implicit part of their practice. Asking about a patient's support network, acknowledging that they may be embarrassed and providing reassurance are all facets of patient-centered care. As Most PCPs align themselves with notion of patient-centered care these quality indicators may be considered too simplistic. However, implicit aspects of practice are also indicators of quality. The issue

is that these aspects of practice may not be implicit for all PCPs and even more importantly they may not be considered implicit from the perspective of the patient.

### ***Implicit to practice***

There were 8 quality indicators that PCPs felt were implicit to practice or that they considered were already in place (QI 1, QI 5, QI6, QI10, QI11, QI13, QI14, QI 15). When something is implicit it can all too often be hidden thereby making it difficult to assess whether it is in place or not. In addition the finding that these aspects of care were implicit to practice is based on the views of PCPs. If patients were to assess whether these quality indicators were in fact in place they may not conclude that alternative treatment options were discussed (QI 5) or that confidentiality policies were made explained to them (QI13). This is discussed in more detail below.

### ***Results of the thematic analysis***

Analysis of focus groups and interviews with PCPs regarding the service user-developed quality indicators resulted in the following three global themes:

- examination of practitioner skills
- determining the accountability of primary care
- the importance of commissioning and incentives.

These are discussed in turn below while an extensive literature review has not identified any other studies that have elicited the views of PCPs regarding quality indicators for youth mental health.

### **Global theme: Quality indicators examine practitioner skills**

#### ***Comparisons with existing literature***

Variation in practitioner confidence and skills has been reported by previous qualitative studies about provider views of general health problems in youth primary care, but not specifically mental health (Kang et al. 2003; Jacobson et al. 2001). Practitioners have acknowledged that there is a gap between their own and young people's understanding about confidentiality (Jacobson et al. 2001) which is supported by the findings of this study. Andersen and colleagues' (2003) qualitative study found that doctors and nurses working in A&E felt their skills were often inadequate to effectively manage young people who had attempted suicide which in part complements the finding that practitioner confidence in managing young people's mental health problems varied. About half of the PCPs who took

part in the focus groups and interviews had an interest in mental health which may indicate that they are more likely to feel confident managing a young person with mental health problems compared to those that had no special interest or additional training.

Quantitative studies based on adult samples have also reported that GPs ability to detect mental health problems varies (Goldberg & Huxley, 1980; Millar & Goldberg, 1991) and is dependent on their knowledge, skills and attitudes (Marks et al. 1979). A qualitative study found that practitioners recognise limitations in their skills when managing depression in older adults (Burroughs, Lovell, Morley, et al, 2006). The finding that mental health training has a positive impact upon attitudes towards managing mental health problems in primary care has been previously reported in quantitative studies based on adult samples (Cape 2008). The results of this study suggest that the relationship between training and attitudes may also apply to managing youth mental health problems.

GPs acknowledge that their role in managing depression in adults is often limited to prescribing medication (Chew-Graham et al. 2002). Similarly, GPs feel that they have to contend with a lack of time while needing to adopt holding strategies to manage depression in adults (Dew et al. 2005). The findings of this study show that these factors also apply to young people with mental health problems but they reveal a more complex picture. Because PCPs consider young people with mental health problems to be a challenging group to deal with it can be argued that implementing the patient-developed quality indicators in primary care would challenge the existing skills of practitioners and expose the limitations on the extent to which they feel able to work with young people with mental health problems.

### ***Implications for practice and policy***

Practitioners can feel alienated and uncomfortable with young people (Jacobson et al. 2002) which may also contribute towards a practitioner's response to young people with mental health problems and can become a self-perpetuating problem. The less comfortable they feel the less likely they are to want to work with this group which can then also affect their willingness to attend training courses on this group. Although a good appraiser should identify any training needs, mental health training is not compulsory after registration. In addition, there are few opportunities for PCPs to work in CAMHs. Practitioners choose which continuing professional education courses to attend. The attitude of practitioners towards dealing with mental health problems in young people plays an important role in determining their support for the quality indicators. Those with more interest, skills and confidence in working with this group may be more accepting of the quality indicators.

Although educational programmes for practitioners are largely unsuccessful with adult samples, they have been shown to improve GP knowledge, skills and self perceived competency in dealing with adolescent general health (Sanci et al. 2000) and GP detection rates of psychological distress and suicidal ideation in adolescents (Pfaff et al. 2001). They have been shown also to reduce depression scores in young people (Asarnow et al. 2005). Improved training opportunities should therefore be offered to primary care practitioners to increase their skills in managing mental health problems with this group.

## **Global theme: Determining the accountability of PC**

### ***Comparisons with existing literature***

The finding that voluntary and educational services should also play a role in the management of youth mental health problems is supported by the NSF core standard and standard 3 for children and young people (Department of Health, 2004). These standards recognise the voluntary sector's ability to 'deliver services with more flexibility and at times possibly better than has been previously done by the NHS' (Department of Health 2004a). Practitioners have been reported as endorsing the view that specialist practitioners are more appropriate for mental health problems for both adults and young people (Bindman et al. 1997; Lester et al. 2005; Anderson et al. 2003). This complements the finding in this study that some practitioners felt specialist services would be more appropriate than primary care in the management of mental health problems in young people.

Practitioners cited competing interests as a barrier to implementing the quality indicators and this was also reported as a reason for not taking on quality indicators in a US survey of mental health providers (Valenstein et al. 2004). Problematic communication between primary care and specialist services has been reported by primary care practitioners managing mental health problems in young people (Richardson et al. 2007) and adult patients (Sigel & Leiper, 2004).

GPs prefer to rely on their own clinical judgment, as opposed to questionnaires, when assessing depression severity (Dowrick et al. 2009) which seems to indicate that they question the usefulness of clinical assessment tools. This study has found that PCPs questioned the validity of the quality indicators because they task PCPs with undertaking activities they consider to be implicit in their practice and/or difficult to implement. These concepts have not been previously reported for either young people or adults, possibly because they are aspects of quality improvement that have been developed by young people with less emphasis on input from professionals.

### ***Implications for practice and policy***

Although participants felt that many of the indicators were implicit to primary care practice<sup>25</sup> a minority also acknowledged that patients may not share the same view. This illustrates the differences between the perspectives of patients and practitioners. Practitioners are the providers of a service and as such do not have an objective view of how services are received. Implementation of quality indicators requires that practitioners acknowledge that what they consider to be implicit part of their practice may in fact not be experienced as such by young people. This approach challenges practitioners to be reflexive about their assumptions as to how their practice affects young people.

The findings suggest that the changing interface between primary care and mental health services may have impact upon the implementation of quality indicators. PCPs were concerned about waiting lists for and communication difficulties with specialist teams. Since this study was conducted the new Improved Access to Psychological Therapies (IAPT) initiative has been developed and it is envisaged that this programme will reduce the need to refer to specialist mental health teams and reduce waiting list for psychological treatments. IAPT is not for those under the age of 18 but for young people over 18 IAPT services might help practices to meet the quality indicators associated with access to talking therapy<sup>26</sup>.

Special interest groups have published practice guidelines to improve access to therapies for particular groups. These address the barriers that are specific to particular patient groups including Black and Minority Ethnic patients, perinatal patients, older people, offenders, and those with learning disabilities. Children and young people are included as a special interest group but guidelines for best practice for this group have yet to be published by Bury PCT. Some PCTs are extending the inclusion age to patients aged 16 and above which may ensure that talking therapies are available for younger patients.

Implementation of the patient-developed quality indicators requires practitioners to focus on the mental health needs of young people. This challenges the ethos of general practice which is to treat all health problems of all age groups. Different health problems and groups of patients are competing for resources in primary care. It may not be realistic to ask practitioners to focus on the needs of a particular group of patients.

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<sup>25</sup> Quality indicators (11, 13, 14 and 15)

<sup>26</sup> Quality indicator 7 - *access to talking therapies needs to be made easier as an alternative to medication* and Quality indicator 8 - *referral times for young people should be as short as possible to reduce the stress experienced while waiting for an appointment*



### **Global Theme 3: Importance of commissioning, incentives and guidance**

#### ***Comparisons with existing literature***

Practitioners' concern about legal issues regarding the management of mental health problems has been previously reported for adult patients (Dew et al. 2005) and young people (Richardson et al. 2007). However, the findings from this study relate to different aspects. Dew and colleagues (2005) found that GPs were more concerned about missing physical as opposed to mental health problems. Richardson and colleagues reported that practitioners were concerned about legal issues associated with the then recent warning about prescription of anti-depressants for young people. By contrast this study found that some PCPs felt restrictions dictated by clinical guidance may inhibit practitioners in making their own decisions according to the patient-developed quality indicators. Other PCPs were more confident and preferred to rely upon their own clinical judgment rather than follow clinical guidelines. This latter finding is supported by a recent study by Dowrick and colleagues who reported that GP valued their own clinical judgements over formal clinical assessment measures (Dowrick et al. 2009).

### ***Implications for policy and practice***

A major obstacle to delivering PBC has been the lack of timely and accurate data about the populations served by practices (Lewis et al. 2007). If accurate data about the mental health of young people are not collected their needs are in danger of being overlooked by primary care, irrespective of whether practices are aware of the patient-developed quality indicators or not. On the other hand, if young people with mental health problems were to be identified as a significant group this would enable implementation of the quality indicators locally. World Class Commissioning will require PCTs to be even more aware of the needs of their local populations and to plan services accordingly (Gillam & Lewis, 2009). Undertaking a joint strategic needs assessment will enable PCTs to collect better quality data to pass on to commissioners at practice-level. Although patient involvement in commissioning has yet to be established, patient-developed quality indicators could form part of a needs assessment to guide the commissioning of patient-centred services. Three of the quality improvement initiatives (presented in chapter 2) state that young people's needs and views should be incorporated into the planning and delivery of services but there is a lack of formal evaluation to determine whether this is taking place or not in primary care.

The quality indicators are aimed at individual practitioners. Assessing quality at the level of individual practitioner does not take into account the wider factors affecting the care given by individual practitioners. If practitioners are to be assessed by the quality indicators they (practitioners) would need to have some level of control over how they are implemented. For example, improving access to talking therapies for young people (quality indicator 7) involves factors that are outside the immediate control of a practitioner. Since the literature shows that practitioners are supportive of those quality indicators that they feel are useful and that they have some influence over (Valenstien et al. 2006), as practices become more involved in commissioning decisions through the launch of the new GP consortia (Department of Health 2010), this may enable them to align their purchasing decisions with quality improvement initiatives such as the patient-developed quality indicators.

The finding that clinical guidance restricts practice needs to be interpreted within the context of the study. Thirteen of the twenty seven participants had a special interest in mental health and they may as a result not be indicative of the average practitioner, who without a specialist interest or knowledge may benefit from clear guidance. They may not want or wish to 'think outside the box' and so it would be prudent to have guidance in place that helps the majority of practitioners. However it does need to be acknowledged that existing guidance applies to primary care practitioners across the board with different skills.

The QoF mental health indicators were developed in consultation with patient groups (SANE and Depression alliance) (Lester & Kendrick, 2007). As discussed above, if the dynamics of the involvement are not carefully managed, patient involvement may be tokenistic and not have any sort of meaningful impact on outcomes. That the patient-developed quality indicators do not feature prominently in the QoF (NHS Employers & General Practitioners Committee 2009) may be used as a reason for practitioners not to identify young people with mental health problems as an important group to treat. Participants felt strongly that their practice is not only shaped by policy but through intuition and experience. GPs may welcome the possibility of having more autonomy over what is discussed and not having to tick boxes during a consultation. If the patient-developed quality indicators are not in place the extent to which a young person's needs are ultimately met then depends entirely upon the skills and attitude of the individual practitioner.

If practitioners are not formally assessed on indicators that incorporate patient views it is questionable just how patient-centred their practice will be. Incorporating patient views into quality indicators chimes with the recent focus on patient experience within quality assessment outlined by the Darzi report (Darzi, 2008) and the new Government White paper (Department of Health 2010). It has been suggested that rotating quality indicators to focus on new areas might be the way forward for quality improvement (Lester & Majeed 2008). This could shift the focus onto youth mental health and help primary care to deal with the issue of competing demands. i.e. moving onto each health issue and patient group in succession ensures that each area is addressed by the QoF. This method could improve patient involvement in clinical decision making, managing patient expectations and patient satisfaction.

Although PCP views of the quality indicators were assessed through qualitative methods, no formal evaluation was conducted as part of this study. The quality indicators could be further developed into a toolkit to aid implementation. This could be followed up by an evaluation. This will be discussed below.

### ***Development of a toolkit***

A collaborative working group of young patients and practitioners from a group of practices could work together as an expert panel to review the existing quality indicators and develop a tool kit to aid implementation. This tool kit would assist practices in implementing each quality indicators and may include the following:

- Develop links with local services and encourage them to deliver and keep up-to-date literature in your practice.

- Consider designing and commissioning a poster to advertise mental health services in your practice.
- Encourage practitioners to attend training courses on youth mental health
  - Is there a local champion in your practice or a colleague that is well informed about available training and other continuing professional development events?
- Encourage links with CAMHs/CMHTs and youth counseling services
  - Does your practice follow a consultation-liason approach? If not how could you develop this in your practice?
- Consider commissioning IAPT services for young people
  - Is there an opportunity to be involved in joint commissioning of talking therapies for young people within a network of practices?
- Revisit your referral protocol – how do you explain the referral, do you give a young person the chance to ask questions?
- How do you discuss confidentiality, how do you reassure a young person and do you ask about their support network?
- Offer alternatives to medication
  - Does your practice have access to talking therapies, computerised CBT, self-help materials?

An online and a hard copy of the tool kit could be made available for practices to consult through the Royal College of General Practitioners Adolescent Working Party. Further development of the quality indicators could be done through piloting each indicator within a group of practices. Practice teams would agree to implement the quality indicators and be assessed upon the implementation (see below). The groups could be encouraged to share results and learning through a quality improvement network made up of colleagues that participated in the pilot.

### ***Evaluating implementation***

Young service users suggested a number of ways that implementation of the quality indicators could be assessed (see page 181). For a majority of the quality indicators

assessing the patient's experience was the most common method of evaluating whether the quality indicator was in place.

However the way that the data is collected and used needs to be carefully considered. It would be important to have patients collect the data themselves so that the assessment is conducted from their perspective. Young people could conduct pre and post consultation interviews to assess whether alternative treatments to medication were offered and whether reassurance, confidentiality, questions about support network were discussed and referral protocol followed.

Quality indicators that call for information and advertisements to be put in place could be evaluated by a check list. Patients could check for items in place such as the availability of posters and leaflets in the practice about local services. A survey of staff qualifications and CPD training course attendance could be used to evaluate the capacity for youth mental health work and range of services available at a practice. A mystery patient could also be used to check for items in place and assess whether services and treatments were offered during the consultation.

As noted above feedback from patients alone is unlikely to produce changes in the way services are delivered. It may be useful to have a forum whereby patients and practitioners could review the results together and discuss ways to improve implementation of the quality indicators. This could be one way of involving the patient participation group from each practice and would encourage dialogue between practitioners and their younger patients.

### **Strengths of the study**

The main strength of this study is the involvement of young patients as co-researchers. The young people that developed the quality indicators presented them to the practitioner focus groups, speaking about their experiences and discussing why they felt the quality indicators were important to primary care. This may have increased the relevance placed upon the quality indicators. The young people who co-facilitated the practitioner focus groups, myself and other researchers including GP academics were involved in generating the thematic networks for the analysis. This collaborative process between a range of key stake holders improved the reliability and validity of the analysis.

### **Limitations of the study**

The practitioners involved in the qualitative evaluation of the quality indicators had a mixture of special interests. Of the twenty seven that participated, nine had a special

interest in mental health, four had a specialist interest in youth mental health. Fourteen either declared none or had a special interest in a non-mental health related field. As an atypical sample with just under fifty percent having a special interest in the topic, the participants may not have been representative of PCPs as a whole. This is often the case in health services research however, as often those practitioners that agree to take part in an interview or focus group are those that have an interest in the area of the research. In addition, it is important to obtain the views of such 'local champions' because they are the ones that often support new initiatives in primary care.

A second limitation was the sampling strategy. Having multi-practitioner focus groups may have affected the way the participants interacted with each other. Power differentials between GPs and other members of the primary care mental health team could have impacted upon the extent to which nurses and other practitioners felt able to express their points of view (Brown et al. 1999). In retrospect, sampling the groups by profession may have enabled participants to speak more openly and would also have enabled easier comparison with other studies as most of these sampled by professional group. Conducting focus groups with existing practice teams may also have affected the extent to which colleagues felt able to speak openly with one another due to differences in seniority. However, focus groups allow researchers to examine the dynamics within a naturally occurring group. Using existing practice teams allowed me to gain an insight into the way quality indicators and youth mental health are managed within primary care.

A third major limitation was that due to lack of time the results of the focus groups and interviews with primary care practitioners were not fed back to participants. This meant that respondent validation which adds rigor to the methodology was absent although two GP academics were involved in data analysis.

Finally thematic analysis was chosen as the most appropriate method. The young service users had no previous research training. I wanted to use a method of analysis that was both systematic and easy to follow so that they could be involved in the process at all stages of the analysis. Discourse analysis is a more complex method of analysis and as such did not seem feasible to use with young people that had had no previous research training.

I did not choose conversation analysis because it would have involved observing consultations between young people with mental health problems and PCPs. As people often act differently in consultation than they do when with their peers, I felt it was better to enable young people and PCPs to explore their own views outside of the context of the consultation.

## **Assessing the quality of the methods**

I will draw upon the five main guidelines outlined by Mays and Pope (1995) to assess the quality of the qualitative research conducted in this study. As this thesis employed mainly focus groups I will also refer to the concepts put forward by Kidd and Parshall (2000) to judge the quality of focus group methodology used in this research. As many of these guidelines are also used to assess participatory research I will highlight how these apply to the principles of quality in participatory research (Koch and Kralik 2006).

- Respondent validation – participants are consulted on the extent to which they agree with the researchers interpretations.

The focus group participants confirmed the initial interpretations during the wave 2 focus groups. These groups also generated more data as participants gave additional reasons for their views. For participatory research the notion of credibility is assessed by the extent to which the co-researchers view the findings as meaningful and not only the audience. As well as acting as co-facilitators for the focus groups, co-researchers were involved in coding meetings, developed the quality indicators during participatory research groups and reached agreement through nominal groups. For the latter two stages of the research the results were presented to the co-researchers to confirm that their approval. This means that the results were interpreted collaboratively (Koch and Kralik 2006).

- Triangulation – more than one method or data source (i.e. from different interest groups) is adopted to investigate the research question.

The quality indicators were developed using data from focus groups and interviews with young people and nominal group technique. It was also considered important to include young people from a range of different backgrounds and experiences to ensure a comprehensive sample. Primary care professionals were consulted on their relevance and appropriateness. Therefore, perspectives from two different groups (young people and professionals) were sought.

- Transparent and comprehensive reporting – the methods used to recruit the sample, collect data and conduct the analysis are clearly reported and justified.

In the methods chapter I have attempted to provide a clear account of how the interpretations were developed from the data using examples. I also provided examples of

the extensive memos that were written during the analysis which form part of the audit trail. Kidd and Parshall (2000) consider the reliability of focus group methods to be determined by the following factors: the extent to which the same group is convened on more than one occasion and multiple moderators or coders are used. Respondent validation should be achieved using the same groups or groups of similar composition to judge the credibility of the themes that have been derived (Kidd and Parshall 2000). For the focus groups with young people each group was repeated with the same participants for the purposes of respondent validation (discussed above). This was not the case with the professionals. For the focus groups with young people and professionals each had a facilitator a co-facilitator. Kidd and Parshall (2000) assess internal consistency on the basis of whether one team member has responsibility for the analysis and has been present at all the focus groups analysis research and team meetings. This thesis meets this standard as I have been present throughout the entire research process.

- Reflexivity – an awareness of the ways that the researcher and the research process impact on the way that data is collected and interpreted. The position of the researcher and prior assumptions and experiences are accounted for so that differences between the researcher and the participants can be assessed by the audience.

Participatory researchers draw heavily on the notion of reflexivity and its relationship to action and collaboration (Koch and Kralik 2006). They assess the extent to which the reader is able to grasp what is going on while researching. This means that the entire process is viewed as a reflexive exercise. I have attempted to provide a number of examples of my personal reflections and how these impacted on my approach to the research, co-researchers, data collection, analysis and management of some of the difficulties experiences during this study.

- Relevance - This involves assessing whether the research adds to our knowledge or strengthens existing evidence and the extent to which the findings can be generalised to another setting. This is facilitated by providing a detailed account of the research so that the audience can determine whether the research would be applicable in a different context. This is often referred to as *transferability*.

I have attempted to provide evidence that through conducting participatory research, young service users can develop face valid quality indicators for primary care. I also hope to have provided a clear description of the participants and the context of the study. Finally, the



discussion chapter suggests comparisons with existing literature and implications for policy and practice.

## **Conclusions**

Three different concepts - non- help seeking is appropriate, help seeking as risk, and help seeking as functional - can add to our understanding of youth help seeking for mental health problems. These themes show the complexity surrounding the decision to make an appointment, drop into a clinic or approach a member of one's social network.

The patient-developed quality indicators illustrate the needs of young people with mental health problems as a quality output while their implementation will require professionals to examine their own skills. The accountability of primary care in dealing with youth mental health was questioned by professionals. This indicates that meeting the needs of young people with mental health problems presents a particular challenge to primary care practitioners. The quality indicators were aimed at individual practitioners but the results suggest that the indicators cannot be implemented without consideration of the role played by commissioning of primary care services and incentives for practitioners. The quality indicators could be further developed through the design of a tool kit to aid implementation and a pilot evaluation.

This thesis adds to the literature on patient involvement in quality improvement and youth help seeking for mental health problems by engaging with participatory methodology. The work was guided by critical theory, my own experiences, and collaborative working between young service users, researchers and primary care practitioners. The quality indicators and thematic networks are both novel and support existing studies indicating that the findings represent an original contribution to knowledge.

## CHAPTER SIX: SUMMARY AND CONCLUSION

Young people often do not access primary care for their mental health problems (Oliver et al. 2005; Biddle et al. 2004), and when they do they are unlikely to have their problems identified (Haller et al. 2009). This could be addressed by attempting to improve the way that primary care is delivered to this group and one way of achieving this is through the involvement of young people in the assessment and development of primary care.

However, most existing quality improvement initiatives have involved young people through consultation rather than through collaboration, and as a result it is difficult to determine the extent to which these initiatives have reflected the needs and experiences of this group.

Furthermore, young people's views on help seeking and the role of primary care have not been investigated using a participatory research approach, with the result that our current knowledge may well be limited without the contribution of new interpretations based on young service users' experiences.

This is the first study to have developed user-generated quality indicators for managing youth mental health problems in primary care, thereby providing a detailed description of the aspects of quality that young people consider important in primary care. It is also the first study to have explored professionals' views of young service user-generated quality indicators and to have involved young service users as co-researchers in this process, together with the investigation of youth views on seeking help for mental health problems and the role of primary care.

Thirty young service users were recruited and trained to be involved as focus group co-facilitators, members of the analysis team, and youth expert panel nominal groups. Focus groups were conducted with young people, both with and without mental health problems, so as to ascertain their views on seeking help for mental health problems and the role of primary care in treatment. The data was used to generate quality indicators by young service users who then ranked and agreed upon which were most important of these using the nominal group technique. Young service users presented the final sixteen quality indicators to primary care professionals (PCPs) during focus groups which they also co-facilitated. As the data from the focus groups with young people was extremely rich a more focussed thematic analysis was also conducted. Throughout the study young service users and the research team (which included GPs) worked together to collect and analyse the data.

Understanding the process of help seeking requires attention to the social, emotional and cultural aspects of the lives of young people. The findings from this study illustrate the tension between the three overall themes: not seeking help as an appropriate course of

action, help seeking as a risk and finally, help seeking as being useful. This indicated a conflict between wanting to manage problems on one's own versus the realisation that one cannot rely on oneself anymore. It also shows the ambivalence between taking a risk and satisfying a need for support, suggesting that the process of help seeking takes place through the interplay of fears, expectations and need.

The majority of help seeking literature employs survey methods and statistical analysis to describe, explain and predict relationships between variables that have an impact upon help seeking. The findings of this thesis both support and provide alternative explanations for the relationships that have been widely reported as having an impact upon youth help seeking for mental health problems in the quantitative literature. The findings also provide new interpretations and are supported by existing qualitative studies. Involving young service users in the data collection and analysis led to the development of these new conceptualisations which in turn adds to our understanding about the complexities of the help seeking process. As noted above, with regard to quality indicators, these new interpretations are an integral part of the evidence base, and without them the views of young service users would be weakened within the literature.

The sixteen quality indicators that were developed differ from existing quality initiatives for young people in the areas of referral protocol, treatment options and interaction during consultation. These are summarised below:

- Referral protocol: Young service users felt that the waiting time should be reduced; they should be kept up to date on their referral and be given information about what to expect when they see the person they are being referred to.
- Treatment options: alternative treatment options should be discussed before prescribing medication and young people should be able to see a mental health specialist at the surgery.
- Interaction during consultation: PCPs should acknowledge that young people may be embarrassed or feel stigmatised, and PCPs should reassure them that mental health problems are common; PCPs should enquire about patients' social networks; counsellors need to be more interactive.

These results illustrate that exploring young service users' definitions of quality in primary care mental health leads to new interpretations as well as similarities with previously reported findings. This builds upon our knowledge of what encompasses an optimal primary care service and can inform patient-centred practice. It also indicates that not

involving young service users would lead to the development of quality improvement initiatives that neglect their experiences and needs.

The young service-user generated quality indicators presented a challenge for primary care professionals (PCPs) in that they forced PCPs to assess their skills, while bringing about a need to determine the accountability of primary care at the same time as implementation requiring alignment with existing policies and commissioning. Most efforts to improve quality (e.g. through the implementation of clinical guidance, quality assessment or audit) involve elements that are difficult to achieve, and they present practitioners with problems that need to be negotiated. These findings illustrate specific barriers that would need to be overcome to implement quality indicators developed by young-service users.

Assessing practitioner skills is a relatively uniform aspect of quality improvement while it has to be acknowledged that young people with mental health problems represent a complex picture. The combination of belonging to a younger age group whilst having a mental health problem may present PCPs with a particularly difficult set of issues to manage.

Concern about the extent to which primary care should be held accountable for youth mental health problems could be addressed by promoting models of joint working between primary care and the education and social care sectors. However issues of clinical responsibility would still need to be clarified.

This thesis ultimately raises the question of whether young service user views can have an impact on policy and commissioning decisions, and more specifically on practice, and if so, how that can occur. I hope to have shown that through the use of a participatory research design, young service users' views can be meaningfully used to develop quality indicators and can thereafter form part of the evidence base on which policy is based.

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## **Appendix one: Youth Focus Groups Wave 1 Topic Guide**

- 1) Introduce myself and the co-facilitator and give a short summary about the focus group/project.
- 2) Tell them about our own experiences
- 3) Go through group guidelines and ask if they want to add anything to the list.  
Experiences about reasons for getting help or not getting help for emotional problems, what was helpful, what was not helpful you do not have to tell us about what caused the distress unless you feel comfortable doing so. Have a discussion amongst yourselves - I am here to facilitate the discussion and not take part myself so try not to direct your answers to me but to the rest of the group.
- 4) Ask others to introduce themselves for the purpose of transcription.
- 5) Ice breaker exercise - What are the best things about being a young adult? What are the worst things?
- 6) Brain storming - Why do people seek help when they are feeling low or stressed?

I noticed that many of you said that you had experienced some type of emotional distress such as feeling low or stressed – could someone tell me why or why not you would seek help and from where?

What is it like when you go somewhere to talk about this?

- 6) Do people avoid getting help for their stress?

Prompt: Does the stigma/embarrassment stop someone from getting help?

Has anyone had a similar experience?

Has anyone had a different experience?

### **7) Introduce Case Vignette – ask a participant to read to the group**

David is 18 and lives at home with his mother. Although she he a close circle of friends he has recently been feeling cut off from everyone and has problems concentrating on his college work. He says that she feels tired all the time, and doesn't want to play football, which is his favourite sport. Although he feels tired he finds it difficult to go to sleep when he goes to bed and wakes up early in the morning. His close friends notice that he is not as talkative as he used to be and he recently told one of them that he feels angry a lot of the time and can't enjoy anything anymore.

What is happening/the matter with David?

Is there anything wrong with David?

What words can be used to describe what he is experiencing?

What should he do?

Do people agree/disagree?

Should he go for help?

Where can he go to get help? (Pick up on each service they mention and ask about each one individually).

Do people agree/disagree?

What else might help?

What does someone that is experiencing this need?

8) Can counselling help?

Has anyone had a similar experience?

Has anyone had a different experience?

9) Can GPs help?

Has anyone had a similar experience?

Has anyone had a different experience?

10) Can medication help someone deal with an emotional health problem?

Do people agree/disagree?

11) Are there any other places that someone can get help, that we have not mentioned?

12) Should someone's parents/close friends know that they are going for help?

***If they are not talking about seeking help***

Has anyone or does anyone know someone who has had to deal with a difficult time in their life? Did they get any help?

Where do you go when you experiencing stress/anxiety/depression?

Can you go to a GP? If no, why not?

## Appendix two: Youth Focus Groups Wave 2 Topic Guide

1) Welcome back and thank-you for coming back today

**2) Go through guidelines and ask if they want to add anything to the list**

3) Ask others to introduce themselves for the purpose of transcription.

Is there anything that anyone has thought about since the last session that they would like to discuss or comment on or add to something that was said in the last session?

4) Feedback themes from Wave 1 analysis

I am going to feedback to you what I think are the main themes coming out from last weeks' discussion. I want you tell me if you agree with what I am saying and let me know if I have got it right or wrong – that is fine either way! **And tell me why you agree with me or not.** I also want you to add anything that you have thought of or let me know if there is anything that you want to change from what you said last week.

6) Brian-storming Exercise – Flip Chart

How do you know whether someone is suffering from a mental health problem?  
What are the signs?

Low  
Tired

### Having sleep problems

What about feeling  
Feel anxious  
Depressed

What about experiencing a  
Panic attack or  
Self-harm

What are the needs of someone who feeling this way?

Should they go for help? Why? Why not?

How do you decide that you need to get help?

Where should they go for help?

Can a GP recognise these signs?

Can a GP identify that someone needs further help?

If not a GP then who can recognise them? A counsellor? Why?

10) What questions should they ask?

Prompt: What should a GP/primary care worker say to get someone to talk about his or her feelings?

11) What should a GP/primary care worker say to make someone feel better?

12) Ideal service

If anything was possible to create – could someone describe what would be the ideal place that a person could go to for help with handling their stress?  
Who would be there, where would it be, what would it be like?

**End ask them if they would like to take part in the YEP next year – as a group then approach people individually**

**Appendix three: Youth Demographics Form**

This information will be used to build a picture of the types of people we have been talking to. Your name is not on this form so we cannot identify what information you have given us. You do not have to fill in any sections if you do not wish to do so. Please note that this form covers two sides.

**1) Gender: Please tick one box:**

female  male

**2) Age: in years.....**

**3) Ethnicity:** Please indicate which of the following categories best describes your ethnicity by ticking the appropriate box (taken from the 2001 Census):

A. WHITE

British

**Irish**

Any other white background (please specify)

.....

B. MIXED HERITAGE

White and Black Caribbean

White and Black African

White and Asian

White and Other Mixed Heritage (Any other mixed heritage background, please specify)

.....

....

C. ASIAN or ASIAN BRITISH

Indian

Pakistani

Bangladeshi

Any other Asian Background (please specify)

.....

.

D. BLACK or BLACK BRITISH

Caribbean

African

Any other Black Background (please specify)

.....

E. CHINESE or OTHER ETHNIC GROUP

Chinese

Any other (please specify)

.....

**4) Current qualification:**

Please indicate the title of your course that you are currently registered on:

MA/MSc  BA/BSc  HND/Diploma  BTEC  G/NVQ

Other (please specify).....

Are you registered as:

Full-time  or Part-time

**5) Please describe your parents' occupation as best you can:**

Father.....

Mother.....

Step/parents.....

Guardians/others.....

**6) Parents postcode address; e.g. N16.....**

7) Have you experienced any of the following emotional health problems? (You can tick more than one)

Depression     Manic episode(s)     Anxiety     Panic attack(s)

Phobias     Obsessions     Eating disorder

Self-harm     Attempted suicide     Psychosis

Other (please specify).....

**8) Have you been to any of the following places for help with an emotional health issue? (You can tick more than one)**

GP     Counsellor via GP     Counsellor (other)     Group Therapy

Accident and & Emergency     School service     Student services

Psychiatrist     Psychologist     Drop in/ Walk in centre

Other (please specify).....

**9) When did you seek help for an emotional health issue?**

Currently receiving help     1 month ago     2 months ago

6 months ago     1 year ago     2 years ago

Other please specify.....  
.....

**Thank-you for filling out this form – Please return it to Tanya or (name of co-facilitator)**



Appendix four: Frequency distribution of scores and median values from round 1 (R1) and round 2 (R2) ranking by indicator number (S) 1-46																								
	R1 S1	R2 S1	R1 S2	R2 S2	R1 S3	R2 S3	R1 S4	R2 S4	R1 S5	R2 S5	R1 S6	R2 S6	R1 S7	R2 S7	R1 S8	R2 S8	R1 S9	R2 S9	R1 S10	R2 S10	R1 S11	R2 S11	R1 S12	R2 S12
	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	
	1	1	2	2	1	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	
	1	1	2	2	1	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	
	1	1	2	2	1	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	
	1	1	2	2	1	2	1	1	1	1	1	2	2	2	2	1	1	1	1	1	1	1	1	
	1	1	2	2	2	2	1	1	1	1	1	2	2	2	2	2	2	1	1	1	1	1	1	
	2	1	2	2	2	2	1	1	2	1	2	2	2	2	2	2	2	1	1	1	1	1	1	
	2	2	2	2	2	2	2	1	2	1	2	2	2	2	2	2	2	1	2	1	2	1	2	
	2	2	3	2	3	2	2	2	2	1	2	2	4	2	2	2	2	2	1	2	1	2	3	
	2	2	3	4	4	4	2	3	2	3	2	3	4	4	3	2	2	2	2	2	2	2	3	
	3	2	4	4	4	2	4	2	3	2	4	2	4	4	3	3	2	3	2	2	2	5	3	
Median	1	1	2	2	1.5	2	1	1	1	1	2	2	2	2	1.5	2	1	1	1	1	1	1	1.5	
	R1 S13	R2 S13	R1 S14	R2 S14	R1 S15	R2 S15	R1 S16	R2 S16	R1 S17	R2 S17	R1 S18	R2 S18	R1 S19	R2 S19	R1 S20	R2 S20	R1 S21	R2 S21	R1 S22	R2 S22	R1 S23	R2 S23	R1 S24	R2 S24
	2	2	1	1	2	1	4	5	2	2	5	5	1	2	1	1	1	1	2	4	2	4	2	1
	2	2	1	1	2	2	3	4	1	1	5	4	2	2	2	2	1	1	2	2	3	3	2	2
	2	2	1	2	1	2	4	4	2	2	4	4	2	2	2	2	1	2	2	4	4	4	2	2
	1	2	2	1	1	1	2	2	2	2	2.5	3	1	2	2	2	1	1	1	2	1	3	1	2
	1	1	1	1	1	1	2	3	2	1	3	5	2	1	1	1	2	1	4	1	3	1	2	1
	3	3	1	2	2	5	5	2	2	3	4	1	1	2	2	1	1	1	1	2	3	3	2	2
	1	1	1	1	2	2	3	4	2	2	4	4	1	2	1	2	1	1	2	1	4	3	1	1
	3	2	1	1	1	2	3	3	2	2	4	4	1	1	1	1	1	1	1	2	3	3	2	2
	1	1	1	1	1.5	1	4	4	2	2	3	2	2	1	1	1	1	1	3	3	4	4	2	2
	2	4	1	1	1	1	4	4	1	2	5	4	1	1	1	1	2	1	4	4	4	4	2	1
	1	2	1	2	1	2	4	4	4	1	5	4	2	4	1	1	1	1	4	4	4	4	2	2
	1	2	1	1	1	2	4	4	1	2	4	4	1	1	1	1	1	1	1	1	2	2	1	1
Median	2	2	1	1.5	2	2	4	4.5	2	2	4	4	1	1.5	1	1.5	1	1	1.5	1.5	3.5	3	1.5	1.5
	R1 S25	R2 S25	R1 S26	R2 S26	R1 S27	R2 S27	R1 S28	R2 S28	R1 S29	R2 S29	R1 S30	R2 S30	R1 S31	R2 S31	R1 S32	R2 S32	R1 S33	R2 S33	R1 S34	R2 S34	R1 S35	R2 S35	R1 S36	R2 S36
	1	1	1	1	1	2	1	1	1	1	1	1	1	2	1	2	1	1	1	2	1	1	1	1
	1	1	1	1	2	2	1	1	1	1	1	1	1	2	2	2	1	1	1	2	1	1	1	1
	1	1	1	1	2	2	1	1	1	1	1	1	2	2	2	2	1	1	1	2	2	2	2	1
	1	1	1	1	2	2	2	1	1	2	1	2	2	2	2	3	1	1	1	2	2	2	2	2
	1	1	1	1	2	3	2	2	1	2	1	2	3	3	2	3	1	1	2	2	2	2	2	2
	1	2	1	1	2	3	2	2	2	2	1	2	3	3	2	3	2	1	2	2	2	2	2	2
	2	2	1	1	2	3	2	2	2	2	2	2	3	3	2	3	2	2	2	2	2	2	2	2
	2	2	1	2	2	3	2	2	2	2	2	2	3	3	3	3	2	2	2	2	2	2	2	2
	2	2	1	2	3	3	2	2	2	2	2	2	3	3	3	3	2	2	2	2	3	2	2	3
	2	2	1	2	3	3	2	2	2	3	2	2	3	3	3	3	2	2	2	3	3	3	3	3
	3	3	2	2	3	3	3	2	3	3	3	3	3	3	3	3	2	2	4	4	4	4	5	4
	4	3	2	2	3	3	3	2	4	4	3	3	4	4	3	4	3	3	5	4	4	4	5	5
Median	1.5	2	1	1	2	3	2	2	2	2	1.5	2	3	3	2	3	2	1.5	2	2	2	2	2	2
	R1 S37	R2 S37	R1 S38	R2 S38	R1 S39	R2 S39	R1 S40	R2 S40	R1 S41	R2 S41	R1 S42	R2 S42	R1 S43	R2 S43	R1 S44	R2 S44	R1 S45	R2 S45	R1 S46	R2 S46				
	1	1	1	1	1	0	1	1	1	1	1	1	1	1	2	1	1	1	1	3	0			
	1	1	1	1	1	1	1	1	1	1	1	1	1	1	3	1	2	1	1	3	2			
	2	1	1	1	1	1	1	1	1	1	2	1	1	2	3	2	2	1	1	4	3			
	2	1	1	1	1	1	1	1	1	2	1	1	2	3	2	2	2	1	2	5	4			
	2	2	1	2	1	1	1	1	2	2	1	1	3	4	2	2	2	2	5	5	5			
	2	2	1.5	2	1	1	1	1	2	2	1	1	3	4	2	2	2	2	5	5	5			
	2	2	2	2	1	1	1	1	2	2	1	1	3	4	2	3	2	2	5	5	5			
	2	2	2	2	1	1	1	2	2	2	2	2	1	4	4	2	3	2	5	5	5			
	2	2	2	2	1	2	2	2	2	2	2	2	1	4	5	2	4	3	5	5	5			
	2	2	2	2	2	2	2	2	2	3	2	2	1	4	5	3	4	4	5	5	5			
	4	5	3	3	2	3	3	4	3	4	2	2	4	5	4	4	5	5	5	5	5			
Median	2	2	1.75	2	1	1	1	1	2	2	1	1	3	4	2	2.5	2	2	5	5	5			

## **Appendix five: INFORMATION SHEET FOR YOUTH EXPERT PANEL**

### ***Developing young people's involvement in mental health in primary care***

#### ***Introduction***

We would appreciate your help in improving the way that general practitioners (GPs) and their staff respond to young people who are stressed. We have been given a grant by the NHS London Region to understand how GP surgeries can be more "youth-friendly" when a young adult comes to them with a mental health problem or worry. So far, we have completed fourteen focus groups and are now preparing to use the information collected to develop guidelines for primary care professionals to use when helping young adults with emotional distress. I would like to invite you to help us with this next stage of the project.

#### **What will we be asked to do?**

You will join a group of ten young adults and be shown approximately 30 statements from the focus groups about what primary care professionals should do in order to help someone dealing with emotional distress e.g. 'GPs should offer counselling.' We will ask you to rank the statements in order of importance (1 meaning very important and 9 meaning least important). You will be paid £30 cash for taking part. You will be supported to work both individually and in small groups by members of the project team.

#### **When and where will this take place?**

The groups will take place in July and August 2004 at the Health Services Research Department, DeCrespigny Park, London SE5. The groups will start at 10am and finish at 4pm. We will give you lunch and refreshments.

#### **What are the benefits to me?**

You will be paid £30 for attending an all day group and will have your travel costs reimbursed. Taking part in the groups could help provide new experiences and skills and you will be able to meet other young adults with similar experiences. You will also have the chance to get your views heard and play a crucial role in helping practices provide a good service for young people. We would also like to show you the results of the project and give you a copy of the final report.

#### **Is it confidential?**

All the information you provide us will be treated in confidence. The groups will be recorded by audiotape and held secure. They will then be typed out, taking care that it will not be possible for anybody other than the research team to know who said what and the team will keep this information confidential. Nobody will be able to identify you from what is written. The tapes will be destroyed at the end of the study.

#### **Who can I talk to if I want more information?**

Throughout the course of the study the person to contact with all your questions is the researcher on the project: **Tanya Graham**. She can be contacted on 020 7848 0906.

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

**We hope you will participate in the project.**

## **Appendix six: INFORMATION SHEET AND CONSENT FORM FOR FOCUS GROUPS WITH PCPS**

Developing young people's involvement in mental health in primary care

### ***Introduction***

You are being invited to take part in a research study designed to improve the way that general practitioners and their staff respond to young people who are stressed. Before you decide it is important that you understand why the research is being done and what it will involve for you. Please take time to read the information provided here and discuss it with people if you wish. Ask us if there is anything you are unclear about or would like more information. Please take your time to decide whether you would like to take part.

### **What is the purpose of this project?**

To produce and evaluate a set of quality indicators that will go towards improving the way that GPs and other primary care staff to deal with young people who are stressed. This will help GPs to provide a better and more effective primary care service for people aged between 16-25 years old that come for help with mental health problems or worries.

### **What are we asking of you?**

Twenty-five young service users have been involved in the development of a set of quality indicators for youth mental health in primary care. We are interested in getting your views and opinions on the appropriateness of these quality indicators. Some of the young service users that took part in developing the quality indicators will first present the quality indicators to you and then you will be asked to comment on them by taking part in a focus group with 6-8 other primary care practitioners. We will pay your locum expenses for the entire day.

### **Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time, without giving a reason. This will *not* affect your job at the surgery in any way.

### **Will the information I provide remain confidential?**

If you consent to take part in the research any information you provide us with will be treated in confidence. The focus groups will be recorded by audiotape and held secure. They will then be typed out, taking care that it will not be possible for anybody other than the research team to know who said what and the research team will keep this information confidential. Nobody will be able to identify you from what is written. The researchers who have listened to audiotapes will ensure that confidentiality is maintained. The tapes will be destroyed at the end of the study.

### **Who is funding the research?**

The Institute of Psychiatry is carrying out the research and they have been given a grant from the Department of Health to fund the project.

### **Who can I talk to if I want more information?**

Throughout the course of the study the person to contact with all your questions is the researcher on the project, **Tanya Graham**. She can be contacted on 020 7848 0906.

**What will happen to the results of the research?**

This research project will be published in an academic journal and presented to the NHS for changes in youth health policy. The final report will be made available to. Please let the researcher know if you are interested in receiving information about the project.

**Who has reviewed this project?**

The project has been approved by the South London and Maudsley Trust Ethical Committee (Research) and by the following primary care trust ethic committees: Lewisham, Lambeth, Southwark and Croydon.

**What do I do now?**

If you are interested in taking part please contact Tanya Graham on 020 7848 0906 or by email on [t.graham@iop.kcl.ac.uk](mailto:t.graham@iop.kcl.ac.uk). Tanya will then confirm your place at the workshop and send you details of the date and venue in due course.

If you are happy to proceed, please sign the enclosed consent forms. Keep one for your records and send the other back to:

Tanya Graham Box 28,  
Section of Primary Care Mental Health  
Health Services Research Department  
DeCrespigny Park  
London SE5 8AF

If you would simply like to know more or have any questions please do not hesitate to call or email Tanya on the details above.

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

**I hope you will participate in the project.**

## CONSENT FORM

Developing young people's involvement in mental health in primary care: towards consumer produced quality indicators

Please initial boxes

1. I confirm that I have read and understand the information sheet dated April 2005 for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason, without my medical care or legal rights being affected.

3. I agree to being recorded by either video or audio equipment whilst in the discussion group and realise that the tapes will be used by a researcher to help them keep a record of what was said. Tapes will not be played for any other purpose and destroyed once used in this way. No one other than the research team will have access to these tapes, which will be kept, in a locked cupboard.

4. I agree to take part in the above study.

Name .....Date..... Signature.....

Person taking consent

(If different from researcher).....Date.....Signature.....

Researcher.....Date.....Signature.....

## Appendix seven: Topic guide for focus groups and interviews with PCPs

Are there any quality indicators that you feel are already in place?

To what extent are these indicators already in place/are you doing these already?

Can you please give some examples?

Prompt: such as information about local services, poster, waiting list reduction

Access to mental health specialists at the surgery (counsellor/psychologists/CAMHS workers/

Which would you like to be doing more of?

Prompt: Are there any that you would identify as being a priority for the practice?

What factors make it difficult to implement the indicators?

Prompt:

General Medical Services (GMS) contract

Time pressure

Resources

Are they unrealistic/unnecessary?

Which are unrealistic?

Which are less unrealistic?

To what extent should primary care be the setting for the management of young people's mental health problems? Is it fair to expect primary care practitioners to work to these quality indicators?

Could the indicators be used to gain points via the contract?

Prompt: such as patient survey/ enhanced services/ patient communication?

Could the indicators be incorporated into the contract?

How important are these indicators to the Primary Care Trust (PCT)?

How will PCT-commissioning play a role?

How could the practice benefit from incorporating the indicators?

Would patients benefit? Are there any benefits?

Do the indicators need to be better defined? If so which ones?

Which of these would be relatively easy to implement?

Which are more difficult to implement?

How could they be incorporated into a toolkit for practices to address the needs of young people with mental health problems?