MARGINALISED GROUPS AND HEALTH SERVICES: PROVISION, EXPERIENCES AND RESEARCH ISSUES

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Acknowledgements

Abstract

This commentary is a reflective account of research published over the last eleven years. It highlights the themes underlying the publications and tracks the development of the author's research skills while simultaneously showing the impact of the publications on knowledge in the areas covered.

Three themes from the research are highlighted. The first relates to the research participants in the publications who include detained and voluntary psychiatric patients, minority ethnic groups and carers. Members of these groups can all be described as marginalised or disadvantaged and are known to sometimes have poorer experiences of health and health services. Their experiences are the second theme. The commentary then highlights some issues in the research as the third theme, in particular the often unrecognised impact of the methods used and concepts employed on the research findings. Although some limitations of these are described, the commentary demonstrates the complexity of the concepts and issues and suggests that these should be acknowledged more widely. A possible way forward is by greater involvement of service users and altering the research perspectives.

The next section discusses the impact of being a contract researcher during a period of greater recognition of the importance of listening to patients and their carers. This has had a bearing on both the research and the author's development as a researcher.

The commentary then provides reflections on the individual publications submitted detailing the roles played by the author and recent research in the area. Some overarching ethical issues are also discussed.

The ultimate aim of all the research presented here has been to improve the experiences of health service users and it is concluded that in each case it has contributed, even if only in a small way, to this aim whether to the academic literature or more directly to service improvement.

Contents

1   Introduction

The papers presented here are selected from publications produced over an eleven year period whilst employed as a contract researcher in health services research. Short-term contracts necessitated changes in research topics and participant groups but simultaneously afforded me the opportunity to develop as a researcher in a variety of areas. In this commentary I shall highlight three recurrent themes in my publications: marginalisation and health services; users' experiences of services; and issues in the research. I will also describe the development in my research skills and my contribution to knowledge in these areas. Lastly I discuss the impact of being a contract researcher. Volume II contains copies of the publications.

2   Themes

Looking at my publications as a whole, two principal themes immediately stood out and appear in all the publications selected for this commentary. These themes; marginalised groups, for example psychiatric patients and minority ethnic groups, and their experiences and provision of health services were major foci in many of my publications, often appearing in the titles. Such themes are important since they represent aspects of considerable significance when researching health service provision and its improvement. Once these themes were identified they then informed the final selection of papers to include here. The last theme of research issues, for example, the impact of the methods adopted and ethnic group categorisation, emerged on re-reading the selected papers. It became apparent that despite working across a variety of topics, I had repeatedly identified and discussed several issues and concerns with the research methods thereby also justifying their inclusion in this commentary.

2.1   Marginalised groups and social exclusion

The first theme to be highlighted is the participants, who despite their diversity, may be described as marginalised or socially excluded. The term marginalised refers to groups or individuals who are on the margins of society and have limited access to social resources. It has much in common with social exclusion (Peace, 2001). There are many ways of characterising social exclusion but in relation to this commentary its key elements fit the definitions provided by Burchardt et al (1999) and Tsakloglou & Papadopoulos (2002). Burchardt et al (1999:229) stress being 'resident in a society but for reasons beyond his or her control he or she cannot participate in the normal activities in the society that he or she would like to so participate'. Tsakloglou & Papadopoulos (2002:212) describe 'social exclusion' as 'chronic cumulative disadvantage'. Marginalisation and social exclusion therefore refer to the exclusion of some groups of society from both material and social resources with implications for their experiences of illness and of health services (Bywaters & McLeod, 1996). For example, there is considerable evidence that compared to the majority population, minority ethnic groups in the UK and in many other countries have overall poorer health outcomes (Bhopal, 2007). Similarly people with mental health problems suffer from poorer health and receive poorer physical health care (Thornicroft et al, 2010).

Using these definitions, most of the participants in my publications might be described as marginalised or socially excluded. It is widely accepted that users of mental health services (Huxley & Thornicroft, 2003), problem drinkers (Room, 2005) and minority ethnic groups (Modood, 1997) suffer from social exclusion and disadvantage in terms of health, employment

and access to services (Social Exclusion Unit, 2001). Disadvantage is perhaps more frequently associated with these groups but there is now growing evidence of disadvantage associated with unpaid or informal caring such as isolation, poverty, ill-health and discrimination (House of Commons, 2008; Carers UK, 2009). For example, Heitmueller & Inglis (2007) have highlighted that carers may suffer financially not only because of non or reduced participation in the labour market but also because they earn less for similar jobs than those not also in a caring role. It should also be highlighted that being a member of one disadvantaged group increases the likelihood of belonging to another disadvantaged group (Howard, 2001).

On the other hand, it should not always be assumed that belonging to one of these groups is always associated with disadvantage and that social exclusion is inevitable. Clearly this is not always the case and one of the underlying arguments of this commentary is that people cannot be defined by one characteristic alone. The significance of any attribute depends on other personal characteristics and the situation. Indeed, belonging to some minority ethnic groups has been shown to be protective from some of the negative aspects of caring (Janevic & Connell, 2001).

Research perspectives on marginalised groups

In some of my publications and much research in the social and health sciences, these groups can appear as 'problems' needing to be dealt with. This problem-solving perspective has an impact on the research questions, the types of answers sought and methods adopted. For example, both the excess of Mental Health Act (MHA) detentions in 'Black' ethnic groups and lower health service satisfaction ratings amongst minority ethnic groups (Department of Health, 2009) are viewed as problematic. Such findings need investigation and where possible solutions but sometimes pressure for quick answers appears to lead to accepting a few easy to offer explanations such as institutional racism. Both higher MHA detention rates in some minority ethnic groups and dissatisfaction with services (e.g. Sashidharan, 2001; Department of Health, 2003) have been attributed to racism. It is striking how the DH (2003) report refers to institutional racism in mental health services in a manner suggesting it is well established and requires no comment. This is despite the fact that both the evidence for it and its usefulness as an explanation has been repeatedly questioned (Singh, 1997; Singh & Burns, 2006; Murray & Fearon 2007). There are likely to be several possible explanations for greater dissatisfaction and the over-representation in detentions but alternative or additional explanations (such as poverty and poor educational achievement) are deeply rooted in society and may appear to be considerably more difficult to change than institutional racism. Ironically it is also seen as problematic that some Asian groups (e.g. Chinese) are under-represented in mental health services (Li et al, 1999). Here the concern is that people needing help may not be accessing it. This deserves greater consideration since it may help to understand the over-representation of some groups.

These issues can also be looked at from a different perspective. For example, is being detained under the MHA always purely a negative experience? Could it not be argued that detention can sometimes be necessary and in the patients' best interests? Indeed, there is some evidence that MHA detention is not always an adverse experience (Barnes et al, 2000). Despite identifying many negative effects on patients of compulsory admission, these authors reported that: 'for a significant minority, their experience of compulsory detention left them feeling 'fairly positive' towards services..... compulsion does not have to be a destructive experience – if it is located within an overall ethos of care, respect and dialogue, and a commitment to working together towards recovery' (p13). I would argue that only focussing on the excess of detentions as a problem results in neglect of the underlying question which is why some groups of people are more likely to refuse to come into hospital voluntarily and therefore have to be detained against their will.

My research looking at the under-representation of minority ethnic groups on allied health profession (AHP) degree courses (Greenwood & Bithell, 2005a; Greenwood et al, 2005b; Greenwood et al, 2006) was initiated because of concern that the demographic profile of qualified AHP professionals in the UK showed under-representation of minority ethnic groups. It was based on the idea that health service workforces should reflect local populations (Department of Health, 1995) since it is argued (perhaps a common-sense assumption) that patients and professionals from similar ethnic groups might find it easier to relate to and understand each other. Similarity in ethnic background is expected to lead to greater trust, satisfaction and communication, which in turn should lead to improved patient outcomes (Meghani et al, 2009). There is little evidence here but a recent review of 27 studies in the USA concluded the evidence was inconclusive for positive health outcomes for minority ethnic groups with such patient-provider ethnic concordance (Meghani et al, 2009). There appears to be little such UK research and I have not found any relating specifically to the AHPs but irrespective of any evidence for improved patient outcomes, if minority ethnic students are either unaware of these courses or are failing to gain places on them, then under-representation merits investigation.

Our research question was simple: why were students from minority ethnic groups less likely to follow AHP degree courses? While our findings suggested several possible explanations for this, perhaps the most useful was that amongst some minority ethnic groups there was lower awareness of the content and nature of AHP courses and careers. Significantly under-represented groups were more likely to value having a degree and following scientific careers but were less likely to know the AHPs were degree courses with significant science components.

The complexity of marginalisation

Reasons for both the under-representation on AHP courses, over–representation in compulsory MHA detentions amongst specific ethnic groups and differing experiences of health and health services are undoubtedly multi-factorial and include social, cultural and educational factors but frequently research and policy questions, discussions and findings are over-simplified. Demographic characteristics selected for attention, for example ethnic group, may be isolated from other attributes without consideration of either possible interactions between these characteristics or potential confounding factors (Salway et al, 2009). This is obviously very important since many features of disadvantage and social exclusion are known to co-exist. We drew attention to this in two publications relating to MHA detentions (Greenwood et al, 2006; Singh et al, 2007). Our meta-analyses of detention rates demonstrated that lower quality papers (our quality ratings included control of confounders) identified higher detention rates. Similarly much research fails to highlight that there is only evidence for correlations, rather than causal relationships, between the measured demographic characteristics and outcomes. The direction of association and therefore perhaps the 'real causes' (such as other confounders) may lie elsewhere. Sheldon & Parker (1992: 107) highlighted their concerns about this nearly 20 years ago – 'Rather than observed ethnic variation prompting study for underlying cause, it becomes an explanation'.

A pertinent example in my publications is the role of educational performance in career choices which has considerable impact on participation in higher education. It is well established that some minority ethnic groups perform more poorly academically than others (Bhattacharyya et al, 2003) and are therefore less likely to gain sufficient educational qualifications for degree courses demanding high grades, such as many AHPs. In addition, in the UK, compared to students from wealthier families from all ethnic groups, poorer students tend to perform less well in school and are less likely to go to university (Teaching and Learning Research Programme, 2008). Belonging to minority ethnic groups and material disadvantage are known to be correlated and therefore action required to increase participation of all disadvantaged groups on AHP courses is far wider than, for example, raising awareness of these professions in specific ethnic groups.

Furthermore, patterns of representation in higher education (HE) are complicated making these discussions intrinsically complex. Overall students from minority ethnic groups are over-represented in HE making up 15% of students (compared with less than 10% of the overall population). No minority ethnic groups are under-represented but some like Chinese, Indian and Black African groups are much better represented than others although it is noteworthy that they are more likely to attend 'new' universities especially in London (Bhattacharyya et al, 2003; Connor et al, 2004). In addition there are gender differences within ethnic groups with, for

example, under-representation of female Bangladeshi and Pakistani undergraduates (Bhattacharyya et al, 2003) highlighting the importance of distinguishing both *between* different minority ethnic groups and *within* them.

Certainly in relation to MHA detentions, it has been argued that ethnicity can be viewed as a proxy for disadvantage (Singh, 1997) and since the majority of those compulsorily detained have a diagnosis of psychosis, it is also important to look at relationships between psychiatric diagnosis, disadvantage and ethnicity. Recent research (Morgan et al, 2010) suggests African-Caribbean people living in the UK are likely to be exposed to factors known to increase the risk of psychosis. The authors conclude that this is a 'tragedy' and accusations of racism amongst psychiatrists serve to divert attention from the fundamental reasons for the excess. Possible explanations include: growing up in inner cities; being separated from a parent as a child and adult factors associated with social exclusion such as unemployment, living alone and receiving little support from family and friends (Morgan et al, 2010). Added to this, the 'Count Me In Census' (Healthcare Commission, 2007) showed that African-Caribbean patients are more likely to be referred to psychiatric services via the police or courts making it unsurprising they are less likely to come into hospital voluntarily. African-Caribbean patients referred via 'normal channels' are no more likely to be admitted involuntarily than White patients (Murray & Fearon, 2007: 366). These authors also argue that available evidence does not support either institutional racism in psychiatry or racial discrimination in society in general because some ethnic minority groups, such as Chinese, who are less likely to be compulsorily detained, would also be expected to suffer discrimination.

Marginalised group members are undoubtedly heterogeneous and any associations with disadvantage are likely to be multi-factorial. Concerns have been frequently raised that such groups may have poorer health and experiences of health services than the population as a whole (e.g. Bywaters & McLeod, 1996) and my research presented in this commentary investigates these experiences from a number of perspectives including explorations of patient satisfaction and more widely investigations of patient and carer experiences.

2.2 Experiences and provision of health services

A central theme of my publications relates to patient and informal carer experiences of services and illness. I believe its centrality is partially a result of my interest in this area but is also a reflection of being a contract researcher over the last decade. This theme is explicit in some publications (e.g. Greenwood et al, 1999; Greenwood et al, 2009a; Greenwood et al, 2010) and implicit in others such as Singh et al (2007).

This prominence of 'user' experience is a reflection of the fairly recent recognition of the value of incorporating user perspectives in service delivery. Increasingly it is being acknowledged as pivotal to improving healthcare (DH, 2003) and it is therefore perhaps not surprising that much of my research investigates patient satisfaction and user experience. My publications explore this with a variety of groups ranging from detained psychiatric patients to informal carers of stroke survivors. Investigations of these experiences employed both quantitative and qualitative methods including structured and semi-structured interviews, questionnaires and depth interviews. My four systematic reviews of literature examining detention under the MHA and stroke carer experiences also relate to this theme. While the MHA review did not directly explore patient experience, involuntary admission is coercive and therefore usually considered more negative than voluntary admission. It is noteworthy, however, that inpatient psychiatric care can be experienced as coercive even when voluntary (Gilburt et al, 2008).

Understanding patient and carer experiences of health services is closely related to improving service provision (Farrell, 2004). The publications presented here investigated service provision in different ways. Patient satisfaction and patient experience were explored by interviewing service users (Greenwood et al, 1999; Greenwood et al, 2000; Greenwood & Farmer, 2000). Perspectives on service provision were also investigated in (Farmer & Greenwood, 2001; Greenwood et al, 2006; Singh et al 2007; Greenwood & Bithell, 2005) but with more focus on service providers. The most recent body of studies looked at stroke carers' experiences (Greenwood et al, 2007; Greenwood et al, 2008; Greenwood et al, 2009a; Greenwood et al, 2009b; Greenwood et al, 2010; Greenwood & Mackenzie, 2010a; Greenwood & Mackenzie, 2010b). Details of each publication including my input are provided in Section 5 and in Appendix D.

Most of the research I have undertaken was intended to increase our understanding of the experiences of users of health services with the longer-term aim of informing service provision and thereby helping to improve these experiences. In the course of my research I have identified some rarely acknowledged experiences such as uncertainty and reduced autonomy in carers and in so doing, I hope I have also helped reduce some of the focus on the more commonly investigated areas such as burden and patient satisfaction.

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The first publication included in this commentary investigated psychiatric inpatient experiences and their relationship with patient satisfaction ratings (Greenwood et al, 1999). The approach we used allowed us to highlight the salience of patient experiences, in particular adverse experiences, in determining satisfaction ratings. Much of the research in the area explores the relationships between patient demographic characteristics and satisfaction ratings. We clearly demonstrated that inpatient experiences were more closely related to expressions of satisfaction and dissatisfaction than patient demographic characteristics. We also highlighted that structured satisfaction questionnaires tell us little about patient experiences.

Perhaps my most relevant work in relation to the theme of user experiences is reported in the qualitative interviews with stroke carers and the literature reviews on the same topic. The in-depth interviews with carers (Greenwood et al, 2009a; Greenwood et al, 2010) highlighted two important aspects of carer experiences which have received little or no attention previously. Both uncertainty and reduced autonomy have been investigated in patients with chronic illness (e.g. Gignac & Scott, 1998; O'Connell Baker, 2004) but identifying and highlighting them amongst stroke carers broadens and adds depth to our understanding of carers' day-to-day experiences. In addition, if clinicians are aware that carers may be struggling with uncertainty and reduced control over their lives, they will be better placed to support them. Uncertainty after stroke is likely to remain but clinicians' tendency to stress individual differences and the wide range of possible outcomes after stroke may add to it. Open discussions between carers and clinicians might help carers cope with uncertainty and may also help reduce their anxiety (Greenwood & Mackenzie, 2010a). Similarly many of the facets of reduced autonomy that we identified might be addressed if those offering the services were aware of them.

The same qualitative research was also important for highlighting that carers do not always find being a carer a negative, burdensome experience. We reported that carers often identified positive, rewarding aspects of their role especially with time. Descriptions of positive experiences were often associated with less apparent uncertainly. This raises the possibility that identification of rewards in caring may help reduce perceptions of uncertainty. The challenging nature of caring must not be underestimated but recognising that the role can also be accompanied by positive experiences is important in developing interventions to support carers. Highlighting the rewarding aspects of caring may help carers cope (Grant & Nolan, 1993).

The diversity of carers in terms of demographic characteristics such as age, gender and ethnicity is insufficiently acknowledged (Greenwood et al, 2008). Our research highlighted other rarely identified but important differences amongst carers relating to their experience in caring. We showed that 'established carers' (those who had already been carers prior to their cared-for

person's stroke) and those new to a caring role, differed in the experiences and responses to caring. Established carers not only reported less uncertainty and fewer reductions in autonomy but also tended to identify positive aspects of their role sooner. Such findings highlight the dynamic nature of caring and also suggest that the distinction between carers in terms of their caring experience is important. Both research and clinicians working with and supporting stroke survivors and their carers should take carers' prior caring experience into account.

All three of my systematic reviews (Greenwood et al 2008; Greenwood et al 2009b; Greenwood & Mackenzie, 2010a) have contributed to our understanding of carers' experiences by synthesising the available literature and thereby making it more readily accessible. The most recent (Greenwood & Mackenzie, 2010a) developed the synthesis further conceptually by identifying an over-arching theme of biographical disruption (Bury, 1982; Bury; 1991). The strength of this meta-ethnographic review is that it built on the concepts identified in the research but took the analysis further by summarising carers' experiences with biographical disruption. This concept is well known in relation to people suffering from long-term illnesses but is not usually associated with their carers. Highlighting biographical disruption in carers broadens and enhances our understanding of their experiences and may lead to further avenues of research.

It might also be argued that an additional value of my research is that it reinforces some of the similarities in the experiences of carers and their cared-for. Uncertainty, reduced autonomy and biographical disruption are more frequently associated with patients rather than carers. By highlighting these experiences as issues for both carers and their cared-for supports the argument for more research with patient-carer dyads rather than researching them separately (Coeling et al, 2003).

Looking back over my publications has reinforced how important it is to ask patients and carers about their experiences. Their unique position can inform service providers of what it means to be in receipt of care but I question whether the methods employed always permit in-depth understanding of these experiences. In my opinion, service providers still frequently take the easy option accepting superficial responses which may give the impression most people using services are positive about their care – an issue highlighted many years ago (Williams, 1998).

Additionally in my research experience, patients and carers still need reassurance that their opinions are both valuable and valued but as this becomes more routine they may become more confident in expressing their views. Nevertheless it should be recognised that research has progressed a long way from when it was accepted that providers and clinical staff always knew what was best for patients and their families. The growth of the 'user involvement' movement

has further developed this and although it does not guarantee improvements in services, provided its strengths and limitations are recognised and scrutiny of its impact on research continues, it seems likely research will be better positioned to improve patient experience (Fudge et al, 2008).

2.3 Research issues

Revisiting my publications for this commentary has provided an opportunity to reflect on the range of methods in my research as a whole and on how my thinking about research methods has developed. It has also highlighted both the impact of research methods on the findings and conclusions and has helped me identify several issues which I believe are frequently given insufficient attention in research. In Section 2.3.1 below I highlight the central importance of the research questions and methods and in Section 2.3.2 I explore the often poor conceptualisation of commonly invoked terms such as 'patient satisfaction' and 'carer'. In Section 2.3.3 I go on to d iscuss some possible implications of the routine collection of participant demographic categories.

2.3.1 Research questions and methods

Despite the range of both participants and methods there is one striking theme in my publications: the questions asked and the methods employed determine the sorts of responses or outcomes identified. Faulkner & Thomas (2002: 2) highlight this: 'In pragmatic terms, the value of research evidence is only as good as the questions we ask.' This emphasises the importance of involving service users in the early stages of research who can guide us in questions that matter to them and are likely to improve their experiences (Tew, 2008). Such an approach is also arguably more ethical (Staley & Minogue, 2006) and perhaps in relation to the MHA, if we listened more to what patients say, we might have a better understanding of why people refuse treatment and are therefore sometimes detained against their will.

My research methods initially reflected my academic experimental social psychology background and my later experiences in market and opinion research. The latter in particular was undertaken with little discussion or reflexivity (Willig, 2001) and with no consideration of any philosophical underpinnings of their approach. Most of my earlier academic research relied heavily on semi-structured interviews and on structured, validated rating scales but I was almost immediately uncomfortable with many available published instruments. If I had not had my own doubts, they would soon be highlighted by research participants who quickly described their concerns. This sense of unease is reflected in the first publication (Greenwood et al, 1999) where we compared the Client Satisfaction Scale (CSQ) (Larsen et al, 1979) with both a single rating scale and open-ended questions. My disquiet with scales commonly used in psychiatry and with carers (particularly instruments focussing on burden) has remained in my later studies.

My earliest publication (Greenwood et al, 1999) highlighted several important points concerning the impact of the methods on findings. Like many others using forced-choice

responses (Williams et al, 1998), we reported that approximately three-quarters of inpatients were satisfied ('very or fairly satisfied') with their care but there was also an apparent inconsistency between patients' satisfaction ratings and reports of adverse experiences. Surprisingly six in ten 'satisfied' patients described adverse experiences such as fear, aggression and staff rudeness. This clearly demonstrates that if service providers really intend to improve patient experience, they need to go further than only using responses to satisfaction scales like the CSQ. Such scales are often insensitive and generally do not identify unfavourable experiences. Ideally researchers should employ both qualitative and quantitative methods (Greenwood et al, 1999). This might now be particularly relevant in the UK in the light of proposals that primary care trust (PCT) funding should reflect patient satisfaction ratings (Evans, 2009). Given the tendency for patients to rate themselves as 'satisfied' (Sitzia & Wood, 1997), I would argue that this approach is probably unsound and pays lip service to the reality of patient experience.

Our argument for the employment of composite measures and more frequent use of qualitative measures has been supported by researchers investigating psychiatric patient satisfaction and citing our research (e.g. Powell et al, 2004). More recently, I have become aware of those who argue using both qualitative and quantitative methods in one study should be regarded as a distinct methodology termed 'mixed methods' as opposed to merely a combination of methods. This relatively newly accepted methodological approach is now common in health service research where proponents argue it is justified on pragmatic rather than ideological grounds since it helps researchers 'engage with the complexity of health, health care and the environment in which studies take place' (O'Cathain, 2009: 4). Advocates of this approach have refreshingly open discussions about the need for pragmatism when investigating complex issues such as evaluation of health care services (O'Cathain et al, 2007).

In Greenwood et al (1999) we also argued for a change in focus in the research question with future research concentrating on those patients describing themselves as 'dissatisfied' (Sitzia & Wood, 1997). In contrast with most satisfaction research this approach explicitly assumes some patients may be unhappy with their care even if they do not represent the majority. It might therefore result in service improvements for all patients.

Perhaps the most significant finding from this first publication was the stronger association between *reported experiences* and *satisfaction ratings* rather than between *patient demographics* and *satisfaction ratings*. This suggests it might be more important to focus on improvement of *overall patient experience* rather than on improving services for specific demographic groups. Obviously, there could be associations between patient demographics and experiences (for example if certain ethnic groups are more likely to have adverse experiences) but using multiple regression allowed us to demonstrate that patient experience, rather than

patient group, was most frequently associated with dissatisfaction. Controversially, we reported belonging to an ethnic minority group did not statistically increase the risk of dissatisfaction. Research findings in this area are mixed but a recent study with very large samples (Raleigh et al 2007) lends some support to our research. Raleigh et al concluded: 'Ethnicity had a smaller effect on patient experience than other variables' and went on to say 'Relative to the White British, the Black group did not report negative experiences whereas the Asian group were most likely to respond negatively' (Raleigh et al 2007: 304). Our research was limited as we only compared White and Non-White groups (loosely meaning minority ethnic groups) and Black and White inpatients. Raleigh et al's study demonstrates the limitations of considering such large, diverse groups together.

More recently I have undertaken a number of systematic reviews which is probably a reflection of the huge growth in this type of reviews of research (Moher et al, 2007). Reviews synthesising quantitative research are well-established and important research tools but in qualitative research they remain less well developed (Mays et al, 2005). Reasons for this include practical difficulties resulting from the diversity of methods and lack of consensus about what constitutes good quality qualitative research; differing philosophical assumptions amongst researchers and the fact synthesis may be viewed as in contradiction to qualitative research's main strengths which emphasise uniqueness and depth of data are also concerns (Atkins et al, 2008). Nonetheless, arguments for synthesis remain powerful - if efforts are not made to amalgamate research 'we may fail to move on conceptually and researchers may be accused of re-inventing the wheel' (Sandelowski et al, 1997: 366). Although there are limitations to synthesising qualitative research, its strengths lie in bringing together individual studies which taken alone may not be used in developing policy because of concerns about generalisability. Synthesis reduces this perceived limitation (Mills et al, 2005).

Having undertaken four systematic reviews, although I believe they are valuable, their limitations need recognition. Further research is required to improve understanding of both the impact of sampling articles for inclusion (e.g. purposive or otherwise) and of the value or otherwise of quality appraisal (Popay, 2005). Perhaps it might also be argued that by their very nature reviews tend to encourage the repetition of methods and concepts and exaggerate the importance of ideas or issues that are frequently reported whilst minimising unusual findings. Also because of their apparently scientific approach, it is important to remember that, as with any research, reviews are only as good as the questions asked and the skills of those undertaking them.

2.3.2 Concepts and their application

I also question some of the concepts I have used – for example, the concept of patient satisfaction. The term has not gone without criticism in the literature with some authors arguing

that the term has little value for users of the National Health Service (NHS) (e.g. Sitzia & Wood, 1997). I believe the vagueness of the concept is still insufficiently frequently acknowledged, particularly in policy such as recent discussion about relating PCT funding to patient satisfaction ratings (Evans, 2009). Some of my reservations result from my experience in research interviews, where I found an unwillingness to criticise treatment, especially relating to staff. Generally participants seemed happier expressing dissatisfaction with 'hotel' aspects (e.g. hospital facilities) than with people. Carers and patients (especially inpatients) often began interviews saying they were 'satisfied' with the care received but later would express concern about staff behaviour or their treatment. They often went on to blame underfunding and understaffing suggesting, for example, staff might appear rude but were very busy and under-resourced. This is very similar to the findings of Williams et al (1998) where service users frequently explained away negative experiences attributing blame elsewhere. Maybe the media's frequent reports of insufficient funding in the (NHS) lowers expectations. Participants in my research sometimes alluded to their perception of the (NHS) as 'free' perhaps adding to their unwillingness to criticise services. The situation may be changing, but especially amongst the older people I met in my research, there was considerable trust in service providers and it was assumed the best was being done within available resources.

I also believe that there is also insufficient debate about where and at what point in their care and to whom patients and carers are asked to report satisfaction or describe their experiences. I have met participants currently in receipt of services who were worried that if the staff knew of their criticisms, they or their cared-for person might be victimised. Even after discharge, despite my assurances about maintaining confidentiality others describe negative experiences on audio-tape but still seek reassurance their comments will not be identified. Similarly Tew (2008) reported that patients were sometimes unhappy after discharge to evaluate their experiences of mental health services in case they required inpatient treatment in the future. Some recent research in Denmark looking at satisfaction with outpatient paediatric clinics suggests that satisfaction ratings decrease if made several weeks later (Jensen et al, 2010). Clearly this issue deserves further investigation. Perhaps greater attention should also be paid to who actually asks the questions about satisfaction as in mental health services there is evidence that service users report being 'less satisfied' when interviewed by other users (Simpson & House, 2002). As these authors point out, however, there are two contrasting explanations - this might be because participants felt more able to be honest thus increasing validity, or they might have felt dissatisfaction was the more socially desirable response.

Common use of the term 'burden' in stroke carer research is an example of how research questions and methods and unthinking adoption of a poorly understood term, can have an impact on research. Research with informal carers of stroke survivors has tended to highlight

carer 'burden' (Greenwood et al, 2009). Recently the concept has been questioned (van Heugten et al, 2006) and has been described as both 'broad and vague' (Visser-Meily et al, 2004:602). It has been suggested 'the concept of burden of care be abandoned in favour of more clinically relevant outcomes such as caregiver depression' (Black & Almeida, 2004: 296). Our research supports this since specific emotional outcomes may be amenable to reduction with targeted interventions (Greenwood & Mackenzie, 2010b) making focus on their reduction potentially more beneficial to carers.

Examination of the research also quickly reveals how unhelpful the concept of 'burden' can be when it restricts the focus so other possibly important experiences are ignored or sidelined. This is highlighted by comparison of my qualitative (Greenwood et al, 2009) and quantitative reviews (Greenwood et al, 2008). They seem to tell different stories and it was striking how seldom 'burden' appeared in qualitative literature suggesting if researchers ask carers about 'burden' they are generally told about it whereas asking less focussed questions permits identification of wider issues. For example, rewards or positives in caring were occasionally reported with open-ended approaches. These did not often appear in quantitative studies which often used burden or quality of life scales and overwhelmingly reported adverse consequences of informal caring. Sole reliance on this quantitative research would make it appear there was no satisfaction in caring. Omitting to report satisfactions in care may be especially significant when considering carers' management of difficulties associated with being a carer (Nolan et al, 1996). Our qualitative research demonstrated that carers identifying positive aspects of their experience described less uncertainty and were more likely to identify coping strategies sooner after discharge (Greenwood et al, 2009) suggesting that understanding these positive experiences may help efforts to support carers.

2.3.3   Demographic categories in research

In common with other researchers, I have both reported descriptions of participants in terms of frequently used demographic characteristics or categories such as age and ethnic group and have employed them in data analysis.   Looking back on my research has provided me with the opportunity to query this routine, almost automatic, way of reporting and analysing research. I will argue it is not difficult to see how over time with repeated exposure to standard demographic categories in published research, these descriptive categories might possibly develop exaggerated significance. My questions are twofold. Firstly perhaps the categories may have changed from a means of describing and categorising people, to being 'associated with' certain outcomes and finally to being discussed in such a manner they begin to sound like explanations *in themselves*.   Secondly focusing on them may result in failure to identify other important possibly explanatory factors such as the significance of experience in caring reported in Greenwood et al (2009).

Demographic characteristics of participants such as age, gender and social class are routinely collected in research and recently emphasis has also been put on including ethnicity (Gerrish, 2000). As researchers I believe two main external factors encourage us to gather this information. Firstly we repeatedly see these categories in other publications and perhaps unquestioningly accept their validity and appropriateness. Secondly in order for research to be accepted for publication, we feel under pressure to present participant demographic information often without any theoretical rationale. It is hard to imagine a journal accepting the research I have undertaken without inclusion of participant demographic characteristics. I suspect editors would argue such groupings are necessary in order to judge the generalisability of the findings but if we are unsure of the theoretical significance of demographic characteristics, how can measuring and reporting them help determine the generalisability of the findings? The fact such details appear in results sections (e.g. in Greenwood et al, 2006) but are often not included in either analyses or discussion bears witness to the idea they were not collected with theoretical rationale.

I think there is insufficient debate about these categories both in terms of their meaning to researchers and participants and their limitations. To develop my argument I will focus on two commonly included descriptive categories or terms: ethnicity and carer. I will consider each term separately beginning with a definition and a discussion of how the term has been used in research and policy and finish with some reservations about for each one.

Ethnicity and ethnic groups

Defining ethnicity and its use in health literature and policy

According to Bhopal (2004: 441): 'The word ethnicity derives from the Greek word ethnos, meaning a nation. Ethnicity is a multi-faceted quality that refers to the group to which people belong, and/or are perceived to belong, as a result of certain shared characteristics, including geographical and ancestral origins, but particularly cultural traditions and languages.'

The concepts of race and ethnicity were used interchangeably in health research (Gerrish, 2000) but it is now largely accepted that ethnicity is preferable to 'race'. This is in part because of limited genetic differences between populations and also because the broader concept of ethnicity puts more emphasis on cultural differences. Evidence for continued increase in published health literature using the terms ethnicity and ethnic groups comes from Afshari & Bhopal (2002) and Afshari & Bhopal (2010).

In the social sciences it is now commonly accepted that ethnicity is a socially constructed concept but the manner in which it is used can mean it appears to have a biological basis (Zagefka, 2009). Offering participants distinct mutually exclusive categories and asking them to

select one, may help perpetuate the impression ethnicity is fixed and obvious and it may overemphasise the homogeneity within groups failing to express the complexity of identity (Brady, 2003). Accepting ethnicity is socially constructed is not to say it does not have psychological reality and meaning but I believe researchers have a responsibility to be open and transparent about what they mean by it, to define it consistently and to ensure it is used in a manner that recognises its socially constructed nature.

Although British academic health literature seldom uses race, a brief look at some literature likely to be used in health policy suggests use of 'race' remains common. For example, the Marmot review (2010: 16) states: 'These social and economic inequalities underpin the determinants of health: the range of interacting factors that shape health and well-being. These include: material circumstances, the social environment, psychosocial factors, behaviours, and biological factors. In turn, these factors are influenced by social position, itself shaped by education, occupation, income, gender, ethnicity and race.'

What is striking about this review is the repeated use of the terms ethnicity and ethnic group or sometimes simply 'ethnicity/race'. Any uncertainly about the terms is only mentioned quite late in the report where it states: 'Ethnicity and individual socioeconomic status have many alternative definitions...' (p168).

In a similar vein, the DH publications online section has several publications about the use of ethnic group classification where it appears uncontroversial. For example, their inclusion is justified by the following: 'To contribute to assessments of individuals' needs and circumstances, thereby ensuring that access to services and service delivery can be as personalised and appropriate as possible. For example, insights into a person's ethnic background - or ethnic background of their family - may assist with diagnosis.... To assist with the clinical management of patients as the prevalence and course of many conditions varies by ethnicity' (DH, 2005: 10). However, the danger of placing too much emphasis on these categories when working clinically whilst ignoring other factors has been highlighted, sometimes with tragic results (Witzig, 1996).

Participants' and researchers' understanding of ethnicity

I question whether we know what participants mean when they obligingly self-ascribe themselves to a particular ethnic group. A well-known author in the area commented: 'I describe myself as 'black' in certain circumstances, when I am discussing experiences of racism, or a 'Muslim' to identify my beliefs about health and death, or Indian' to describe my family origin' (Coker (2001: 5). This quote demonstrates the complexity of ethnicity, the central

significance of the situation and ultimately the importance of selection of appropriate demographic characteristics depending on the research questions and hypotheses.

We might further our understanding of participants' understanding of 'terms like ethnicity if we learnt why some people refuse to classify themselves into ethnic groups. Do they refuse because they do not know what is meant by ethnic group? Are they perhaps uneasy about why they are being asked and how the data will be used? Maybe they refuse because they feel confident they know what is meant but feel it is irrelevant to the research and themselves. I imagine participants have a variety of ideas about what ethnicity means and also many reasons for refusal to categorise themselves which probably vary with the situation. Their ideas may not be shared by researchers but I suspect researchers themselves often neither give the meaning of ethnic categories much thought nor hold well-thought out ideas on the subject, simply applying ethnic categories because it is expected. Acceptance of these categories and lack of debate surrounding it reinforces the belief the categories are universally accepted, shared by everyone and are uncontroversial.

In my later research I have tended to adopt the ethnic categories from the 2001 Census (Census, 2001). In my experience of research interviews, if participants question assigning themselves to ethnic categories, it was frequently because they perceived nationality as being more salient to them than ethnicity which they tended to equate with their skin colour or 'race'. Indeed some participants were irritated by the categories on offer wanting to describe themselves as 'British' irrespective of whether they might be described as White or Black as well. 'Race' is now virtually taboo in the social sciences (Bhopal, 1997) but the public in general and research participants may not be happy to accept this. Some participants commented that their 'colour' should be obvious to me or if I was interested in their race, I should ask about this specifically rather than using ethnicity. I do not believe these participants were trying to be difficult; rather they appeared mystified by the process.

Another significant reservation concerns who assigns ethnic categories to research participants – I believe more discussion is needed here. The current consensus is that participants should 'self-ascribe' their ethnicity (DH, 2007) but there might be occasions where asking others, for example those treating patients, to ascribe ethnicity might be more appropriate (Salway et al, 2009). Our assumption when doing the systematic review of ethnicity and the MHA (1983) was that better quality research used self-ascribed ethnicity but since, by definition, MHA detention is done to people against their will, then surely ethnicity in this situation should be ascribed by those doing the detaining? Obviously there are practical difficulties with this particular situation as a variety of people are involved in MHA assessments, but at the very least, more discussion is called for.

Diversity within ethnic groups

There is also a tendency to ignore the heterogeneity within groups and to refer to all members of ethnic groups as the same as if there are no within group differences making the value of the groups in research questionable (Mackenzie & Crowcroft, 1994). This extends beyond differences in for example deprivation but includes categories such as gender. It was notable many of the publications concerning the excess of 'Black' people detained under the MHA in our review, either seldom mentioned gender or did not report it in the analyses. This deserves further consideration with maybe exploration of gender-specific and ethnic-gender-specific explanations for the excess of detentions. Perhaps too by asking participants to assign themselves to these categories or by categorising people in this way, we emphasise difference and help to maintain the 'them and us' and 'in-group – out-group' distinctions social scientists have long regarded as unhelpful. By offering them apparently neat, discrete categories we may be reinforcing between-group and minimizing within-group differences (Bradby, 2003).

We should also not be afraid to point out similarities between ethnic groups (Salway et al, 2009). For example, in my research many issues raised by Asian psychiatric patients and carers are described by psychiatric patients in general and are not specific to any ethnic groups (Greenwood et al, 2000). One particular quote from this study exemplified this: 'I'm a human being first of all, I'm definitely Asian, but I am also British and I am a Buddhist' (p 400). Focussing on similarities in experience might help improve experiences for all patients.

The importance of within group differences was apparent in my publication relating to attitudes to careers in the AHPs where there were clear gender differences within some ethnic groups but not others. For example, overall female participants in general were more likely than males to say they wanted 'to do something for society' but gender differences between Black African and Black Caribbean students were large whilst differences between male and female Asian students were small. Likewise, patterns were similar in respect to participants wanting careers 'helping people' with Asian males and females being more similar than males and females in other ethnic groups (Greenwood & Bithell, 2005a).

This has similarities with research looking at suicide rates among different ethnic groups which concluded: 'We did not find general ethnic group differences, but we did find variations in rates of suicide by age, gender, and ethnic group' (Bhui & Mackenzie, 2008: 418). However, perhaps what is most striking about this publication is that although the authors clearly state that ethnic group alone does not distinguish these groups in their suicide rates and they also mention social exclusion and unemployment, they then argue for policy that improves interaction between

mental health services and users from minority ethnic groups. It seems whatever such authors report, ethnicity is given possibly exaggerated prominence.

Ethnic categories: limitations and reservations

Malterud et al (2009) have described some general concerns that researchers looking at marginalised groups (including minority ethnic groups) need to consider. Firstly there may be methodological issues: for example, looking at the prevalence of a disease in a specific demographic group necessitates a target group that is well-defined, stable and identifiable. This is not true of some minority ethnic groups which may be affected by the fact perceptions of ethnic group membership may change as attitudes towards race relations shift. Such perception can also even change with the order of questioning (Kósa & Ádány, 2007). Further evidence of the problems with self-identification of ethnic group comes from the USA. In the 2000 USA Census when it was possible to give multiple answers on the question of racial identification, 7 million people identified themselves as members of more than one race – almost 800,000 said they were both White and Black (Schwartz, 2001). Minority ethnic group members may also be less willing to participate in research limiting the generalisability of findings (Sheikh et al, 2009).

Kósa & Ádány (2007:290) sum up the situation arguing that regarding ethnicity as a proxy for 'complex health determinants' and 'dissecting these determinants into separate items' is probably the most fruitful way forward. They go on to conclude 'In short simplistic categorizations such as 'race' and 'ethnicity' lead to simplistic research conclusions and, sooner or later, to simplistic policy measures. They are certainly inappropriate in our world of ever increasing complexity' (p 297).

Carers

Defining the term carer and use of the term in health literature and policy

Another category that has appeared in both research and policy with increasing frequency over the last decade is that of carer (also referred to as informal carer and caregiver). Although some authors have noted that carers do not like the addition of the word 'informal' to carer (Nolan et al, 1996) the term has tended to remain in much of the literature and I adopted it in many of my publications primarily to distinguish them from paid or formal carers.

The expression carer was first used in UK public policy in the 1990's in the Carers (Recognition and Services) Act (DH, 1995). In the latest legislation carers are defined as:

'a person (aged 16 or over) who provides or intends to provide a substantial amount of care on a regular basis for an adult or a disabled child. The person may or may not be a relative and may or may not be living with the person for whom they are caring.' (DH, 2005)

Since then has become commonplace in both policy and research. But as I suggested in Greenwood (2009) the extent to which the public has adopted it is less clear and this may also help explain the low uptake of welfare benefits as carers may not associate themselves with the term. This could be a reflection of their ambivalence about the expression 'carer' and unwillingness to formally adopt the 'carer' role.

It is noteworthy how frequently carer participants in the papers covered in the two systematic reviews concerning stroke carers (Greenwood et al, 2008; Greenwood et al, 2009) were either not defined at all or the participants were all spouses who were then described by researchers as carers. I suspect this may be the result of insufficient discussion about precisely what is meant by carer and perhaps an assumption spouses automatically become carers in some situations.

Uncertainty about the term was apparent in our own stroke carer research (Greenwood et al, 2009a; Greenwood et al, 2010). During participant recruitment and it was clear some potential participants did not, at least initially, identify themselves as carers and were more likely to see themselves simply as, for example, spouses. They also sometimes struggled to say how long they had been a carer as although the stroke was usually very sudden, the caring role had sometimes developed gradually with other chronic health conditions (Nolan et al, 1996). With spouses it had frequently started as mutual dependence on each other although the balance may now have shifted.

Having used the term in my own research, it would be difficult for me to argue it has no meaning but in order to improve understanding of carers' experiences, it is important we investigate what these carers understand by 'carer'; how they see their role; what activities they regard as being those of a carer and how these might differ and overlap with being for example, a partner and finally at what point, if any, friends or relatives of someone requiring care and support begin to describe themselves as primarily 'carers' as opposed to other relationships.

Our recent meta-ethnographic review (Greenwood & Mackenzie, 2010a) highlighted that becoming a stroke carer can be associated with realisation that caring has had a fundamental impact on roles and relationships often changing from spouse or adult offspring to carer. This change and the features associated with these different roles can have considerable impact on carers. Improved understanding here might throw light on when carers would be most likely to want and accept support. It seems also possible that research where we encourage participants to think of themselves as carers, may highlight their changed roles and may therefore have an impact on their relationships (Greenwood, 2009). Better understanding of what being a carer means, might also offer insight into the often difficult experiences and emotions carers go through when they cease caring.

Caring and ethnicity

There is little research relating to the impact of caring on different ethnic groups but increasingly the need to measure explicitly the impact of cultural values on caregiving experiences, rather than relying on ethnic group membership, is being recognised. This highlights the limitations of using large ethnic groups as descriptors when trying to understand a complex process such as informal caring. A recent review by Knight and Sayegh (2010) had several important, relevant conclusions. These authors claim there is a common core caring experience for all ethnic groups but dimensions such as familialism and individualism do not necessarily fit easily with large ethnic groups and that attention should be paid to sub-group differences, particularly in relation to factors that might influence stress and coping. Different cultural groups may have different coping styles, attach different meaning to social support and vary in how they express emotional distress. Knight and Sayegh advocate using mixed methods and less reliance on self-reports of health outcomes. They conclude: 'To date, theory development and empirical research indicate that the role of culture in influencing caregiving outcomes is more nuanced and complex than imagined a decade ago. Cross-cultural research and evidence-based practice should meet this complexity head on rather than retreating to the use of stereotypes and simplistic categorical assumptions' (Knight & Sayegh, 2010:11).

Carers: limitations and reservations

Finally and importantly, it is worth considering whether the rather non-specific term carer adds anything to our understanding of the experiences of those in a caring role if their diversity is not stressed. The limitations of treating carers as an homogenous group was highlighted previously in our review (Greenwood et al, 2008) and our qualitative research (Greenwood et al, 2009a; Greenwood et al, 2010) which suggested older and experienced carers may respond differently to caring from younger carers. This may reflect the differing degrees of biographical disruption undergone by these groups (Greenwood & Mackenzie, 2010a) but whatever the reason, their experiences may be very different. However, the dangers of also not recognising some of the common experiences of carers for informing policy should also be recognised (Nolan et al, 1996).

3   Reflections on the impact of being a contract researcher from 1997 to 2010

Academic background, employment and training and their influence on my research

My first degree in the late 1970s was a BSc in Biology & Psychology and was immediately followed by an MSc in Social Psychology, both at Exeter University.

This academic background had considerable bearing on my research, especially initially. The psychology element was largely experimental and the biology was a traditional course based around taxonomic classification. I learnt little about qualitative methods. My MSc by research entitled 'Stereotypes of the Scottish, Welsh and Irish' was purely quantitative using structured questionnaires and recordings of accented speech to gauge perceptions of these three nationalities. Already I was investigating diversity.

Non-research employment

My first paid employment was as a trainee market research executive at Market & Opinion Research International (MORI). The training I received proved very useful for my later work as I received instruction in developing and using structured and semi-structured interviews, questionnaire construction, sampling and focus groups. Although I learnt a lot, much of the work was restrictive with questionnaires being replicated year after year to allow for temporal comparisons so I left my full-time post at MORI to work freelance both for them and several other organisations including the Greater London Council. The diversity of my clients during this time required interviewing a huge range of people including MPs, captains of industry, journalists, teachers and parents of 'disruptive' children. These experiences have all been useful in my later academic career. During this period I was also lecturing part-time for the University of Maryland in Iceland.

I enjoyed teaching and my career then shifted to lecturing in social sciences in Further Education (FE) and Higher Education (HE). Again, the experience was invaluable as teaching social science, especially psychology, at a variety of levels from A-level to Access, BSc and Masters level, ensured I consolidated a sound grounding in psychology. It also meant I developed a critical approach to the literature since teaching students, especially mature students, often from non-traditional educational backgrounds and from a range of ethnic groups, offered fresh, often sceptical perspectives on research.

Contract research posts

After about ten years of teaching, I moved onto my first part-time (0.6) research contract lasting nine months evaluating an alcohol detoxification service. This was the beginning of the

research focussed phase lasting almost uninterrupted for thirteen years at St George's University of London (SGUL) and more lately in the joint Faculty of Health and Social Care Sciences (FHSCS) of Kingston University and SGUL. My involvement in research with marginalised groups can partially be explained by personal interest and my previous academic experiences but the primary explanation was probably the availability of research funding which in turn was a reflection of the zeitgeist. My earliest paper (Greenwood et al, 1999) arose from research financed with Patients' Charter funds. The systematic review of the MHA (1983) was funded by the DH and was a direct response to planned changes in the MHA (2007) whilst the research looking at under-representation of minority ethnic groups in the AHPs was a reflection of recruitment problems at that time (Park et al, 2003).

My research career has also coincided with greater acceptance of patients' experiences and satisfaction as valid outcomes (e.g. Thornicroft & Tansella, 1996) and the importance of 'users' to service development (Fudge et al, 2008). Although user involvement is now generally accepted, further work is still required since the term lacks precision and critical debate is also needed on the purpose of such involvement as well as better evidence for its benefits (Fudge et al, 2008).

It is noteworthy that whilst studying psychology in the 1970's, those taking part in research were referred to as 'subjects' but are now usually known as 'participants'. This change seems to have gained momentum after publication of the British Psychological Society's 'Code of conduct and ethical principles' (1991) and was highlighted later in medical literature (e.g. Boynton, 1998). This terminology may reflect changes in the balance of power from those being 'researched' or 'experimented on' to participants having greater control over the data produced. Promoters of the term also argue 'participant' implies greater 'consideration and respect' (Chalmers et al, 1999: 1141).

My research with carers also mirrors the growing awareness and interest in carers both in research and policy. This may in part also be prompted by the realisation that carers save the economy a huge amount of money (Carers UK, 2009) but carers also need to be supported because without this enormous, largely unpaid workforce, health and social care services would struggle to meet demand (Arksey & Hirst, 2005).

As a result of being a contract researcher I have moved around topics and health disciplines and have undertaken research with psychiatrists, general practitioners (GPs), stroke physicians, psychiatric nurses, community nurses, allied health professionals and social workers. Usually for the purpose of recruitment I have sat in on meetings for community mental health, stroke, multidisciplinary and assertive outreach teams and have also spent hours on psychiatric and

stroke wards as well as GP surgeries. These periods of unstructured observation have been very enlightening, increasing my respect for those working in sometimes difficult circumstances.

I have also witnessed human experiences a lab-based researcher would not see. The horrors of alcohol withdrawal and the appalling side effects of some antipsychotics are lasting memories but I have also been humbled by informal carers and simultaneously privileged to be let into their lives. Meeting these people, repeatedly reminded me of their enormous diversity and the risks of regarding diagnostic and social groups such as 'carers' or 'psychiatric patients' as homogenous.

I was generally either solely or mainly responsible for recruitment and have spent a long time explaining research and going over informed consent with potential participants. In total I have recruited well over a thousand participants. This experience has made me consider at length people's motivations for participating in research. Sometimes they spontaneously offer reasons – for example wanting to 'give something back' in gratitude for care they or a family member have received. Others express disappointment with their care and hope their participation might improve others' experiences. There appears to be little research here but one study focussing on qualitative research confirmed my impressions. Peel et al (2006) identified the primary reasons for participation in research as being grateful for care received, altruism, a way of voicing complaint, 'nothing to lose' and perceived therapeutic aspects of interviewing.

My participants seldom articulated their reasons for taking part although the majority appeared to enjoy the research process and sometimes took the opportunity to describe issues not immediately obviously related to the research. I am very grateful to them but I still wonder how many did not really understand what they were agreeing to, despite my efforts to explain the studies, their methods and purposes (Greenwood, 2009).

Each research job has opened my eyes to different groups and varied health issues. My latest contract has lasted over four years allowing immersion in the field of stroke carers and consequently permitted greater depth and reflection about the research as a whole. This is exemplified by the fact that I have produced eight publications in the area often with the same colleagues.

Moving across topics and disciplines has both advantages and disadvantages. On a personal level I have learnt a great deal as each new topic required additional background reading and I have been able to transfer and consolidate skills learnt in one environment to another. Conversely there was always a temporary feel and arguably less ownership to these contracts as moving on and changing topics is inevitable. I, like most contract researchers, have primarily

learnt research skills 'on the job' (Collinson, 2000: 162) and only recently have I been offered external training in research methods. There was also often insufficient time for reflective analysis of the research and methods used as I moved rapidly onto different projects with different colleagues. I imagine I was often employed because I had successfully completed and published studies using specific methods. This meant I was encouraged to repeat the same successful methods on new topics, thus not expanding of my research methods repertoire.

This lack of specialisation in one area and the perception of being a 'Jack of all trades' possibly reduces the chances of gaining permanent contracts for these researcher (Collinson, 2000) but maybe it is unsurprising that employers are unwilling to invest in training researchers who are unlikely to remain with them.

Like most academic research my research has been limited by practical issues such as length of the project funding (often paying my salary). I believe being a contract researcher has had a fundamental impact on the studies I have undertaken, presumably with similar ramifications on other contract researchers and ultimately on the quality of research published. Short-term contracts restrict detailed reflection and by their nature are driven by short-term goals - usually project completion and publication. I have been lucky that most of my colleagues have acknowledged my central role in the research and ensuing publications and have readily allowed me to be first author. This has enhanced my chances in gaining other contract research posts but I may sometimes have been regarded as a jobbing researcher paid to do a short-term job and likely to move onto another contract elsewhere.

On a personal level, it was sometimes difficult to feel integrated with the departments where I worked and the contract length often meant that within a year of starting a project, it was necessary to start thinking about the next post, creating uncertainty and a sense of impermanence. The trend towards the use of fixed-term contracts in HE started in the 1970's and was propelled by the necessity to reduce costs (Collinson, 2000). Women are under-represented at senior research grades and over-represented at junior levels (Court et al, 1996). Could it be males are not prepared to tolerate this uncertainty of employment with, for example, the resultant poorer pensions? There is some evidence contract researchers may be less concerned about irregular incomes and poor pension entitlements because they are often supported by a partner (Brown & Gold, 2007) but also many leave this 'career' early due to the insecurity (Collinson, 2000). According to NATFHE (1995) the quality of research output is affected by researchers' worries about job security (cited in Collinson, 2000).

There have been other implications of being a general social science researcher with no real professional identity. Largely by chance, my research career has been health-related which has

meant working closely with a variety of health professionals all with fairly strong professional identities. In some situations such as in data collection, my lack of professional, especially clinical, association has mostly been an asset. In these situations, I could genuinely claim to be neither a member of a health care team nor a health professional. There is some limited evidence that not being seen as belonging to a health profession allows for more open communication and criticism of clinicians (Richards & Emslie, 2000) and certainly my impression is it seemed to enhance data collection because I was not perceived as an 'expert'. This perhaps allowed participants to feel they could describe their experiences in full with few assumptions about my prior knowledge or expertise. Nevertheless, I do not know how I appeared to my participants and my overall appearance and manner might mean I embodied common characteristics of health professionals and perhaps participants restricted what they revealed to me to what they thought I would understand (Tew, 2008).

It is undoubtedly positive that Research Councils UK and Universities UK amongst others have recently (June 2008) produced an updated concordat (available at researchconcordat.ac.uk) for the framework for the career management of contract researchers in HE. If the principles are adhered to both the experiences of the researchers and the research they produce should be improved.

4   Ethical issues – some general comments

Many studies in this thesis did not require ethical approval at the time. Three are systematic reviews and two (covering the three earliest publications) were classed as audit or evaluation and therefore did not need ethical approval, although they were reviewed by the Local Research Ethics Committee (LREC). This may not have been the case if they were to be undertaken now as there remains much ambiguity surrounding what constitutes research, service evaluation or audit (Gerrish & Mawson, 2005). We always followed ethics committee guidelines emphasising that participation was voluntary and refusal would not influence care. Informed consent was gained, confidentiality ensured and information kept anonymous. Clearly such concerns should extend beyond research and should cover all activities irrespective of whether classified as research or audit (Gerrish & Mawson, 2005).

Nevertheless, it has to be remembered that participants here were often inpatients (and some were detained psychiatric patients) making it is possible that some found it difficult to refuse to participate. In light of this, it is noteworthy that in the alcohol detoxification study a slightly lower response rate was achieved with outpatients (where arguably it might be easier to refuse) compared to inpatients (Greenwood & Farmer, 2000).

As I have described elsewhere (Greenwood, 2009) I feel there can be considerable pressure on researchers to achieve high response rates and I suspect that this may lead in turn to researchers putting pressure on unsure or unwilling potential participants. I am uncertain what an appropriate degree of encouragement might be or how this might be measured but I remember clearly an early research project where research team meetings always included updates on response rates. Especially as a fairly new researcher it felt like significant pressure. Nonetheless I think that part of my success in recruiting inpatients was the time I spent on the wards. I spent literally hours on the psychiatric wards becoming a very familiar figure. On occasions past participants would volunteer to recruit other patients because they themselves had enjoyed being interviewed so much. I was certainly approached by patients to ask when they could be interviewed.

The research with informal carers of stroke survivors had ethical approval from the LREC but it was only during recruitment and interviewing and after final interviews that some more subtle ethical issues became apparent. Again much of this is covered in Greenwood (2009) where I describe that despite my best efforts, I remain unsure how much potential participants really understand research, especially qualitative research. Many agreed very willingly and appeared to barely read participant information sheets suggesting they had already made up their minds. This was despite my efforts to explain the study.

Support is increasing for the idea that interviewing carried out ethically and sensitively can have a positive impact on coping (Funk & Stajduhar, 2009). Participants sometimes describe interviews as having beneficial therapeutic effects and some volunteer to take part for this reason. Amongst other consequences, research interviews can provide opportunities for validation, introspection, empowerment, unburdening and a sense of helping others (Funk & Stajduhar, 2009). My experience would tend to support these findings.

5 Reflections on individual publications: background, contexts, methods, my roles and current research in the area

This section contains reflections on my publications in chronological order of publication. I shall describe the background to the research and the roles I played for each publication. Greater detail of my roles and the research skills employed are described in Appendix D. I shall also briefly discuss current research in the area and how it relates to my findings.

5.1 Psychiatric inpatient satisfaction – relationship to patient and treatment factors.
Greenwood, N., Key, A., Burns, T., Bristow, M., Sedgwick, P. (1999) British Journal of Psychiatry, 174: 159 -163.

This publication was one outcome of research that took place between 1997 and 1998 in five acute wards in a large psychiatric hospital and one ward in a district general hospital. The Patient's Charter highlighted the need to improve the quality of care they offered and to make greater use of asking patients what they felt about their care (DH, 1992) and this post was funded with money specifically for this. It was supervised by an academic psychiatrist, Tom Burns, who was also Clinical Director at the psychiatric hospital. Only when the project was completed was I told that this was the third attempt to do the research. Some focus groups had been carried out but I started the project again both liaising with members of the Patients' Forum at the psychiatric hospital about the content of the questionnaire and undertaking a literature review.

I learnt an enormous amount on this project in terms of my research skills such as participant recruitment, questionnaire design and interviewing. Recruitment was very successful - I spent hours waiting around on the wards but it paid dividends because I achieved an unusually high response rate (93.3%) for this sort of research (Sitzia & Wood, 1998; Schroder et al, 2007).

This project also influenced my attitude to psychiatry. My psychology training in the 1970's had included a strong anti-psychiatry element and we were encouraged to read authors such as Thomas Szasz and RD Laing. It is difficult to know exactly how this influenced the research but having spent hours on the wards recruiting and interviewing patients, I gained a much better understanding of the challenges involved in caring for acutely ill psychiatric patients.

In contrast to my expectations derived from my first degree and based on beliefs around social rather than physical causation of mental illness, I was struck how patients with bipolar disorder admitted whilst in a manic phase could be calm and rational and apologising for their behaviour 24 hours after taking lithium carbonate – a simple salt. This transformation was a good lesson

for me in the impact of biologically-based interventions. It helped understand how medical models of mental illness might develop and perpetuate although obviously it does not necessarily explain the original aetiology.

There were other notable, surprising features such as the 'open' wards which in reality were nearly always locked so entry and exit could usually only be gained by key. Initially I, like the patients, had to ask to be both let in and out and could be left waiting on one side of the door for some time giving me considerable empathy with patients. I was told the wards were locked primarily to keep drug dealers out, rather than to keep patients in but, whatever the reason, it was frustrating and demeaning to be dependent on staff for access. A recent review (van der Merwe et al, 2009) of research into the use of locked inpatient wards suggests that although some patients report benefits such as feeling safe, disadvantages included feeling trapped, anxious and emphasised the power of the staff. The authors conclude that work is urgently needed to determine the effects of locked wards.

People were often admitted to the wards in my research when acutely ill and arrived with no toiletries or clean clothes. Unless they were lucky, several days later this was often unchanged. This was inexcusable and furthered their dehumanisation. This experience resonated with other elements of my psychology degree such as the work by Erving Goffman on total institutions (Goffman, 1968).

In terms of my commentary's main themes, this publication relates primarily to the theme of experiences of services (Section 2.2) but it is also relevant to research issues (Section 2.3.1). The semi-structured questionnaire had its limitations but because of its length and variety of questions, I believe it was fit for purpose. The inclusion of both open and closed questions allowed comparisons between responses to different question styles and the findings here first alerted me to the impact different question types have on participants' answers. This study highlighted the limitations of rating scales and the need for a variety of modes of questions when assessing patient experience (Sections 2.2 and 2.3). We also reported that females, younger patients and those detained under the MHA were less likely to describe themselves as satisfied but found no significant effect with ethnic groups. Importantly it appeared that 'features of the hospital stay (such as 'staff want to help' and 'staff have explained treatment') were more strongly associated with dissatisfaction than patient characteristics' (p160). This suggests that, in this situation, experiences rather than patient characteristics were important. Weak associations between patient satisfaction and patient demographics have been supported elsewhere (e.g. Ruggeri et al, 2003) but questions remain about why some patients felt, for example safer or more able to complain than others.

As a result of this research, some practical changes were made. Menus were altered and attempts were made to increase patients' privacy but, against our advice, it was decided to monitor patient satisfaction using a one page, highly structured questionnaire. This achieved a less than 10% response rate and was abandoned.

Another important conclusion from our research was that focus should be put on dissatisfaction rather than satisfaction. Possibly identifying those that declare themselves dissatisfied, will make us better placed to improve patient experiences and will increase the dialogue between services and patients. Disappointingly, this suggestion does not seem to have been taken up in published literature.

This research study has been cited far more frequently than my other publications (85 in Google Scholar early in 2010). Most citations concern the findings and whether or not they have been replicated but some authors have focussed on methodological issues and have agreed that composite (e.g. Powell et al, 2004) or qualitative (Johansson & Lundman, 2002) and open-ended questions are necessary (e.g. Soergaard et al, 2008).

Research on this topic continues but with inconsistent findings. For example, relationships between psychiatric patient characteristics and satisfaction are still unclear (Shiva et al, 2009). This inconsistency is perhaps a result of the different environments and methods used to assess satisfaction, reinforcing the need to clarify the concept and its application.

There are two specific methodological limitations of this research. The first was only including inpatients. Interviews were as close as possible to discharge but it is difficult to determine the impact of currently being an inpatient. Being outside hospital and having the opportunity for reflection may have offered a different perspective and improved our understanding of their experiences but it would have been harder to follow-up patients once back in the community. There is a surprising dearth of discussion about the impact of timing of assessment of patient satisfaction as it might be expected to influence patients' observations about their experiences (Section 2.2).

The second limitation relates to the analysis. In common with many other studies, it was decided to collapse 'fairly satisfied' and 'very satisfied' responses together describing both as 'satisfied'. Dichotomous outcomes were necessary for the statistics we selected but more recently it has been suggested (Collins & O'Cathain, 2003) that there can be considerable differences between those describing themselves as 'satisfied' and 'very satisfied'. The former were more likely to see their care as 'acceptable' or 'sufficient' whereas the latter saw it as

above average or even 'outstanding'. Distinguishing between these groups might have thrown more light on the issue.

Research into overall psychiatric patient satisfaction using generalised scales continues but I question its value. Rather than searching for general satisfaction which may not allow either identification of unsatisfactory aspects of care or ways of improving them, I believe it may be better to focus on specific, often local issues which are probably more easily identified and amenable to change.

I also have reservations that many professionals remain sceptical about whether psychiatric patients (because of the nature of their disorders and the medication they are on) are in a position to evaluate their care. I only have anecdotal evidence for this but one consultant psychiatrist working with problem drinkers commented that it was pointless to give them information about discharge plans because they would forget it. When I suggested providing written information, I was told that their chaotic life styles meant it would be lost. Another psychiatrist insisted that I did not question patients on acute wards about how much time they spent asleep, despite the fact that patients repeatedly told me they were bored and passed time by sleeping. I was told firmly that psychiatric patients need sleep and that I must not question them about it. Overall I remain to be convinced that efforts to ask patients about their care is always intended to lead to improvements as opposed to being demonstrations that organisations are prepared to listen.

5.2 Asian inpatient and carers' views of local mental health care. Greenwood, N., Hussain, F, Burns T., Raphael, F. (2000) Journal of Mental Health, 9: 397- 408.

This was an element of my third research post again working with Tom Burns and it too relates primarily to patient experience. This was an ideal opportunity because it offered involvement in qualitative research in an important area.

This project was unique for me as I took no part in data collection although I was involved with analysis from the start and eventually assumed responsibility for the project and wrote both the report and paper as two of the research team left after data collection. This unfamiliar relationship with the data permitted greater distance from the data and arguably increased my objectivity; perhaps facilitating identification of weaknesses in the research.

With hindsight there were two aspects of this project I would change. Firstly, a British Asian (who described herself as a Pakistani Muslim from Birmingham) was the sole interviewer. Having an Asian interviewer was a deliberate choice and speaking at least one Asian language to facilitate interviewer-participant communication was included in her job description. Obviously in some ways improved communication was likely and an interpreter was only employed once but the researcher herself highlighted that sometimes being obviously a female Muslim, hindered communication and one potential participant refused to be interviewed specifically because of this. Perhaps most significantly, she also thought that being Asian meant assumptions were made about her understanding of issues encountered by Asian patients and carers and these were therefore sometimes not articulated. If several researchers from at least one other ethnic group had been the interviewers, additional and possibly different areas might have been highlighted.

As with Greenwood et al (1999) another potential issue was that participants were current inpatients and carers. Findings might have been different if participants had included outpatients or those who were not engaged with services. Accessing them would have been more challenging and time consuming but their perceptions and interpretations of their experiences might have been different, especially if patients who, despite medical advice had discharged themselves, were included.

The study has been cited in a variety of places (17 Google Scholar citations). Citations have tended to focus on our findings (e.g. Rooney et al, 2006) although our approach has been cited as a strength (Ally & Laher, 2008). It is also mentioned on the Mind website where it is included in a factsheet aimed at mental health professionals working with South Asian people.

The factsheet (mind.org.uk) highlights the diversity of those included in the term South Asian and our findings concerning the participants' understanding of mental health problems and their preference for terms such as 'depression' and 'behavioural' problems rather than mental illness.

I have not identified any new UK research specifically looking at experiences of Asian psychiatric patients and their carers. Greater attention still needs to be given to the huge diversity of those people described as 'Asian British' in terms of their cultures, religions and length of residence in the UK. Services for specific ethnic groups (including South Asian) have been set up although there remains debate about the value of such services which some argue foster separateness and difference (Bhui & Sashidharan, 2003).

5.3   A descriptive evaluation of an alcohol detoxification service. Greenwood, N., Farmer, R. (2000) Drugs, Education, Prevention and Policy, 7: 193 - 202.

5.4   General practitioners' management of problem drinkers – attitudes, knowledge and practice.
Farmer, R., Greenwood, N. (2001) Drugs: Education, Prevention and Policy, 8(2): 119 – 129.

Although published later than Greenwood et al (1999), these two papers came from my first research post. In many ways it was a good introduction to psychiatric research. I was responsible for the development of the entire project from reviewing the literature, refining the research questions, developing the methods, recruitment, data collection, analysis and writing up the research. Funding was for an evaluation of alcohol services but we were also able to collect research focussed data. There were two main elements to the project: GPs' management and attitudes to supporting problem drinkers and an evaluation of local detoxification services. A separate publication came from each component but because they arose from the same project, the publications will be considered together. They relate to patient experience (Greenwood & Farmer, 2000) and service provision (Farmer & Greenwood, 2001).

This project enhanced both my recruitment and interviewing skills. The research involved semi-structured, face-to-face interviews with two different groups: GPs and problem drinkers undergoing inpatient and outpatient alcohol detoxifications. I was fortunate with the GPs' response rate and the vast majority of the sample (87.7%) agreed to be interviewed. Gaining access to GPs was not easy but once with them, they were very forthcoming.

I think the methods used were probably the best for our purposes. Meeting GPs almost certainly increased the response rate (Sitzia & Wood, 1998) and although more time consuming than for example, postal questionnaires, it had the advantage of allowing probing with open-ended questions. We considered telephone interviews but evidence suggests face-to-face interviews are more suitable for longer, complex questions (Carter et al, 2000).

To recruit problem drinkers, I waited in out-patient waiting rooms where they collected detoxification medication and asked them if they would be interested in participating. In all cases it was stressed that they did not have to take part and that non-participation would not influence their care. Potential participants were given several days to consider their decision. This informal approach probably aided the response rate as I met people, explained the research and answered any concerns immediately. I used a similar approach with inpatients. Here I waited on the ward although it was often necessary to return to explain the study, recruit and

interview the patients who were sometimes extremely unwell during the initial stages of alcohol withdrawal.

There were some memorable aspects of this research relating to the wards. Inpatients undergoing alcohol detoxification were on 'Vine' ward – surely no joke was intended as this was a general acute psychiatric ward but it seemed a remarkably apt name. Also the two psychiatric wards were furthest away of all the wards from the hospital entrance - literally out of sight and 'round the bend'.

Looking at the recent research little seems to have changed since our publications. Current evidence suggests that simple, early interventions such as identifying problem drinkers and offering them brief advice can help reduce the need for more expensive, intensive treatment but it is 'only sporadically provided by GPs' (NAO, 2008:7).

A recent review comparing inpatient and outpatient alcohol detoxification suggests that outpatient detoxification is often not achievable by homeless and severely dependent people who require inpatient detoxification with supervised withdrawal (Silins et al, 2008). This is in accord with our study where we found that more dependent, unwell patients were more likely to be inpatients (Greenwood & Farmer, 2000).

The National Audit Office (NAO, 2008) report highlighted that per capita spending on alcohol services is considerably less than for services for illegal drug users. The approximate expenditure by PCTs and Drug and Alcohol Action Teams in 2004 was £217 million with £197 per capita for the estimated 1.1 million alcohol dependent drinkers. This compares with £436 million - £1,744 each for the estimated 250,000 dependent drug users. 'The Alcohol harm reduction strategy for England' (DH, 2004: 40) concluded that here was 'little focus on alcohol treatment especially when compared with drug services. Although the DH has provided an extra £15 million for alcohol services the money was not ring-fenced and not all of it is being used for this purpose (NAO, 2008: 17).

It is also noticeable that there is little published research about the experiences or satisfaction with services for problem drinkers. It is interesting to speculate on possible reasons for this but there is evidence from studies in the UK, Australia and the US that the public think 'high' alcohol users and illegal drug users should all receive less priority in healthcare. Often the justification given is that drinkers' behaviour contributes to their illness (Olsen et al. 2003). Similarly, Beck et al (2003) reported that the German public felt that if medical expenses and research were to be cut, alcohol services should be chosen over other disorders. For the UK, a recent poll (2010) carried out by YouGov for the Sunday Times showed the majority (78%) of

those participating regardless of age, occupation or social class thought that binge drinkers should be made to pay for their treatment if they go to A&E. There is also evidence suggesting that amongst health professionals, people with alcohol dependence are seen as a 'less deserving' compared to other diagnostic groups (Thornicroft at al, 2010).

Another issue about problem drinking is our ambivalence towards alcohol use. Drinking in the West is positively associated with valued and important social occasions but simultaneously, despite efforts to promote the disease model, alcoholism is also stigmatised and seen as a sign of moral weakness (Room, 2005). This negative outlook may be reflected in healthcare providers' and research funders' attitudes.

In conclusion it appears that compared with drug users and other mental health service users, problem drinkers, are not being offered the support they need, despite the prevalence of the problem and its occurrence across most demographic groups.

The publication concerning GPs' management of problem drinkers has been cited (18 in Google Scholar) more than the evaluation. Citations have mostly been academic references mentioning our findings (e.g. Rapley et al, 2006) but it was also used in a report by Alcohol Concern (2002) which highlighted gaps in the management of problem drinkers by the NHS.

5.5 Perceptions of physiotherapy compared with nursing and medicine amongst minority ethnic and white UK students: Implications for recruitment. Greenwood, N., Bithell, C. (2005a) Physiotherapy, 91(2): 69-78.

This was a large project (over 600 participants) and resulted in a report and individual publications focussing on three allied health professions (AHPs) - physiotherapy (Greenwood & Bithell, 2005a), speech and language therapy (Greenwood et al, 2006) and occupational therapy (Greenwood et al, 2005b). Only the first is included here.

The study was a departure from much of my previous research and focussed on perceptions of AHPs as possible careers. It was undertaken because of concerns about the under-representation of ethnic minority students on AHP degree courses and in the professions. An important assumption was that service provision is enhanced if the workforce reflects demographically the population it treats (Meghani et al, 2009). The primary tool was a semi-structured questionnaire and its strength lies in the large sample size and detail with which factors relevant to young people's career choices were explored. We reported differences between ethnic groups and between genders but differences between genders varied with ethnic groups. Perhaps most importantly we identified differences between minority ethnic and White students both in how important they thought it was to follow a degree course and the importance of studying the sciences. Minority ethnic students rated these as very important but were less likely to be aware that the AHPs were degree courses with a strong science component. However, minority ethnic students did associate these features with professions such as medicine and pharmacy making them more likely to consider them over the AHPs.

I moved from the Department of Mental Health (SGUL) to the FHSCS for this project. The research came at an important time in my career providing the opportunity to explore issues around the assignment of ethnic categories in research and also meant I worked with Christine Bithell, Head of School of Physiotherapy FHSCS whose enthusiasm and passion for issues surrounding AHP recruitment gave the research focus whilst her collaborative approach allowed me considerable control over the project. I was responsible for the all elements of the study including recruiting and interviewing students mostly still at school or college – a new departure for me. Originally the research was intended to focus primarily on statistical analysis of UCAS data of applications from different ethnic groups to the various AHPs. Although we included an element of this for the background, I was allowed to develop the research into a much richer project, both altering and adding to the original research question and using a more in-depth approach which helped understand reasons why students might or might not be interested in applying to AHP degree courses.

The research findings were used both to develop new approaches within South West London Workforce Development Confederation (now part of NHS London) in terms of their recruitment strategies and the prospectus for physiotherapy at Kingston University was altered to highlight the scientific, evidence-based nature of their course. The study was summarised in Therapy Weekly both in September 2003 and May 2004.

The research also drew attention to the dangers in cultural stereotypes, in this case the belief that female Asian students were probably not applying to AHP degree courses because of taboos in touching males. In fact, this was seldom mentioned and participants even said this was not an issue. In addition the considerable gender differences within ethnic some groups in attitudes to these professions emerged as a striking but unexplored area.

With hindsight further statistical analyses would have improved the study. If we had had more time, we could have incorporated odds ratios to look at the characteristics that were most associated with specific attitudes to careers in the AHPs but ran out of time.

In order to increase our understanding further, ideally we would have had access to data allowing us to determine whether compared to majority ethnic groups, minority groups were making fewer applications for these courses to the Universities & Colleges Admissions Service (UCAS) or whether they were failing to gain places, despite applying in similar proportions. Unfortunately UCAS were unable to provide us with the data that would have allowed us to answer these questions.

On the back of this research focussing on ethnicity, we gained further funding and went onto look into the potential value of targeting Access students for recruitment into the AHPs. We demonstrated that offering Access students who knew nothing about the AHPs minimal careers information about them, significantly increased the proportions who said they might consider these professions (Greenwood et al, 2007).

There has been little published research in this area since our work, although I have had more requests for copies of the questionnaires from the study and was asked to present our findings more frequently than for any other project. Possibly the fact that there is no longer a recruitment crisis in most AHPs - there are more graduates than jobs in, for example, physiotherapy (Guardian, October 26th 2006) has meant the topic no longer arouses as much interest. If this is the case, it raises the question of how genuine the concern for increasing diversity in these professions ever really was. It serves to emphasise how funding is influenced by several factors not only the most immediately obvious. However, we have recently been approached by the DH

about using our findings in their research looking at ethnicity and the AHPs, so maybe the issue will be given more focus in the near future.

5.6   Ethnicity and the Mental Health Act (1983): A systematic review. Greenwood, N., Singh, S.P., Churchill, R. (2006) www.csip.org.uk/silo/files/ethnicity-report-final.doc

5.7   Ethnicity and the Mental Health Act (1983): A systematic review. Singh, S., Greenwood, N., White, S., Churchill, R. (2007) British Journal of Psychiatry, 191: 99-105.

I moved from the FHSCS back to the Department of Mental Health for this study.

It is arguably the most challenging and controversial but also the most important of all research projects I have undertaken. This was my first systematic review and was therefore very important to my development as a researcher. Undertaking systematic reviews has taught me a great deal about research and writing it up for publication. An unexpected benefit of the process was its impact on me - the degree of scrutiny reviewing requires has helped in writing up research by highlighting the limitations of some research but also providing high quality, well-written examples. This, and having the opportunity to peer review research papers for several journals, has improved my publication writing and demonstrated the importance of ensuring that research questions are focussed and clear.

I was responsible for the entire review although all elements of the method were repeated by others as is usual in such reviews. It was a new and isolating experience as I was unaccustomed to solitary desk-based research. However, I developed both skills in analysis and in critical thinking improving my overall research skills. I have since gone on to do several other reviews using the techniques I learnt here.

Inequalities of service use across ethnic groups are important to policymakers, service providers and service users and the over-representation of Black patients detained under the MHA (1983) has been a huge ethical and political concern for some time. The main theme in these publications is therefore mental health service use and provision. This review was originally funded by the DH to help the development of the latest changes to the MHA (2007) but only began after most of the consultation was over.

Although it is well-established that 'Black' (loosely meaning minority ethnic) psychiatric patients in the UK are disproportionately detained under the MHA, there had been no systematic exploration of differences between ethnic groups, or of explanations offered by authors identifying an excess (Singh et al, 2007). We identified nearly 50 publications fitting our inclusion criteria but only 19 of these were included in the meta-analyses because of different ways of reporting findings. We showed that Black patients were nearly four times more likely and Asian patients twice as likely to be detained as White patients. Explanations offered by

authors for the excesses included misdiagnosis, racial discrimination, higher incidence of psychosis and differences in illness expression but these explanations were seldom supported by clear evidence either presented in their papers or cited from elsewhere.

In relation to this particular review, there were a number of significant issues that struck me about the publications we scrutinised. The first was the poor descriptions of research methods and frequently unsubstantiated explanations for the excess of Black people detained. This drew attention to how explanations without supporting evidence can be perpetuated in the literature and can then become accepted simply by reference back to earlier, often opinion-based publications.

I also wondered whether published statistics on detentions might be being artificially inflated because of publication bias. It is well recognised that it is more difficult to publish research with non-statistically significant results (e.g. Song et al, 2000). In this situation it would mean that researchers not reporting significant differences between ethnic groups in detention rates would find it more difficult to publish. However, despite efforts to find unpublished grey literature with useable data, we were unable to identify any such data that could be included. Frequently it was undertaken in such a poorly controlled fashion or so badly reported that it could not be used.

I was struck by how authors frequently made no attempt to explain their findings when reporting non-significant differences in detention rates between ethnic groups. In fact it might be expected that research contradicting others reporting ethnic differences, would result in greater efforts to explain their findings. Taken together these may mean that published literature gives an exaggerated impression of the excess of detentions of Black patients.

The process of systematic reviewing has made me question the common use of quality assessments. My own experience here and several later reviews has made me aware how difficult it is to evaluate often very diverse methods and analyses using a single, generalised rating scale. Quality in research is a complex concept and is often used in a variety of ways and even experts cannot always agree on how quality should be assessed (Centre for Reviews and Dissemination, 2009: 33). There are also specific concerns about the use of quality assessments in reviews of qualitative research (Atkins et al, 2008). In my opinion reviews using quality evaluations should always be accompanied by clearly stated caveats that such ratings cannot be taken as a standalone measure of quality of research but only in the context of that particular review. Often it seems that this topic is glossed over making it appear that the process is both valid and easily implemented. When undertaking this first review, I had to remind myself constantly that the included publications had been limited by varying journal styles and

restrictive word counts. Obviously there is both good and poor quality published research but some elements of quality ratings may simply not apply to all the research under scrutiny - this may at least partially explain the number of scales and checklists available. Nevertheless, in order to be accepted for publication, some journals demand quality assessment, despite the fact it is not always used meaningfully in the discussion.

This review provides a good demonstration of the importance of the background to the question being asked. Simply looking at the statistics on MHA detentions, reveals an excess in some ethnic groups but it is essential to look at the wider picture and to understand the process of MHA detention before offering explanations for this excess. Research points to the importance of consideration of cultural responses to deviant behaviour and pathways into care. Studies with first episode psychosis patients have found that African-Caribbean families are more likely to seek help for a mentally ill family member from police than from the health-care system. Compared with White patients, they are also less likely to be referred by their GP and more likely to be referred by the criminal justice system (Morgan et al, 2005a; Morgan et al, 2005b). It is therefore perhaps unsurprising that they are less likely to agree to voluntary treatment.

Put simply, the reason that people are compulsorily detained is because they refuse to come into hospital voluntarily which in this case means that compared to White patients, Black patients are more likely to refuse inpatient treatment and to be admitted compulsorily. This change in focus suggests a wider range of explanations, for example, the possibility that White patients are receiving help sooner before they reach crisis point and are unable to accept the need for hospitalisation (Morgan et al, 2005a; Morgan et al, 2005b). Another possible explanation is that Black patients have had bad experiences in hospital and are therefore unwilling to come in voluntarily. This cannot apply to Morgan et al's research as it only included first episode patients but our systematic review gives some support to this idea as we demonstrated that with each successive compulsory admission the odds of further such admissions for Black patients increased when compared with White patients. There are a range of possible explanations here and importantly we should not forget that there might be several operating simultaneously, rather than searching for one universal explanation such as institutional racism.

Perhaps one reason for the popularity of explanations such as racism is that they are easy to offer, vague and restrict focus onto psychiatry rather than society as a whole. They may also sound straightforward to remedy with for example training in cultural awareness. Explanations that lie outside psychiatry such as social exclusion (Morgan et al, 2008) relate to wider society and appear less amenable to change, perhaps making them less popular.

A final anecdotal point is that when interviewing inpatients for the psychiatric patient satisfaction research (Greenwood et al, 1999), I asked them whether they were free to leave hospital. I did not formally collect data but it was striking how many said they were not allowed to leave. A number of 'voluntary' patients claimed they had been told that if they did not agree to inpatient treatment voluntarily, they would be sectioned. I have since identified other research reporting this (e.g. Gilburt et al, 2008) but I am unaware of any research that suggests whether demographic characteristics might be associated with such coercion or responses to it but it further demonstrates the complexity of MHA detention and voluntary treatment.

When this paper was published, the editor of the British Journal of Psychiatry described it as 'a paper that almost everyone will read'. He claimed that it would 'attract interest because it challenges us' (Tyrer, 2007; 188). However, even before the report's publication, there were mixed responses from peer reviewers. One reviewer praised its thoroughness and balanced conclusions but another claimed that important evidence had been omitted arguing that the review should have included case histories of detained Black patients. It was difficult to respond to this as the review was only designed to compare detention rates in different ethnic groups and to identify explanations offered. This was clear from the stated aims and objectives. Case histories, with only data on one patient cannot tell us anything about detention rates.

Initially the DH refused to publish the report (although they eventually put it online) saying that although they accepted our findings, they did not wish to be associated with them. The wider implications of their response is worrying – what other research is not being published for similar unclear reasons? There were no problems getting it published in the British Journal of Psychiatry but reactions to it were strong and Swaran Singh, who appeared on Newsnight (2007) soon after its publication was accused of racism both privately and publicly.

The emotionally charged responses were surprising. The paper simply pointed out that authors offering explanations involving racism had not provided supporting evidence and that the focus on racism was too narrow and restrictive. It appears to be being cited fairly frequently (23 Google Scholar citations) but some future citations may be because of negative responses to it.

5.8 Informal carers of stroke survivors-factors influencing carers: a systematic review of quantitative studies.
Greenwood, N., Mackenzie, A., Cloud, G., Wilson, N. (2008). Disability & Rehabilitation, 30(18): 1329-1349.

5.9 Informal carers of stroke survivors - challenges, satisfactions and coping: a review of qualitative studies.
Greenwood, N., Mackenzie, A., Cloud, G., Wilson, N. (2009b). Disability & Rehabilitation, 31(5): 337-351.

I moved back to the FHSCS after the MHA review to work with Ann Mackenzie investigating experiences of informal carers of stroke survivors. I am very fortunate to have worked with Ann as her support has allowed me to develop as a researcher and focus on an important, interesting area. During my time with her I have not only consolidated my reviewing skills but have developed them further.

These quantitative and qualitative reviews are considered together partly because they cover the same period in the literature but also because their comparison highlights how different research methods produce different types of answers. Both relate to the themes of experiences and service provision as experienced by carers, a group that are increasingly being recognised for their very important role (House of Commons, 2008).

Early on in my post I identified a gap in the literature and applying the skills in systematic reviewing that I had developed in my last project, albeit in a very different area, seemed a good idea. Studies on stroke carer experiences had also increased markedly over the last decade making it a good time for synthesis of the research.

It is recognised that looking after stroke survivors at home can impact negatively on informal carers and the aim of the quantitative review (Greenwood et al, 2008) was to identify carer and stroke survivor characteristics (e.g. age or degree of disability resulting from the stroke) associated with commonly reported carer outcomes (e.g. emotional distress and reduced quality of life). It highlighted how poorly carers were defined and also how little research had moved on since earlier reviews (e.g. Low et al, 1999). Both carer psychological characteristics and survivor disability have been shown to be associated with carer outcomes but the research's atheoretical nature and failure to acknowledge diversity of carers, survivors and their situations made it difficult to draw general conclusions.

The qualitative review (Greenwood et al, 2009a) followed the quantitative review and was suggested by the editor of the journal Disability & Rehabilitation once the quantitative review was in press. Searches identified about half the number of relevant papers compared with the quantitative review and although there were similarities in the findings, the qualitative literature

provided a fuller picture of carers' experiences. I drew attention to the fact that thematic analysis, a method reliant on highlighting common themes in qualitative data, was applied commonly, possibly exaggerating similarities between carers' experiences whilst minimising differences. This is particularly important as much research fails to recognise carer diversity (Greenwood et al, 2009b).

Overall, although there continues to be more quantitative than qualitative literature, the emphasis has changed slightly from using quantitative outcome scales to allowing carers to describe their experiences in their own words. Both methods have merit but a combination offers a fuller, more useful picture. However, quantitative research has tended to rely superficially on the same concepts e.g. 'burden' but frequently measured differently and with slight differences in meaning (Visser-Meily et al, 2005). As I argued earlier (Section 2.3.2), I believe this focus has hindered understanding of stroke carer experiences. Qualitative research, whether intended to explore carer experiences or to evaluate the impact of interventions is a very important method, possibly even essential. The review also reported how the qualitative studies were often 'part of a larger' quantitative study and appeared as an afterthought, perhaps to increase publication output. This may then reflect on research quality which in turn influences our understanding of carer experiences.

There have been a few reviews since ours. The most relevant focuses on the longitudinal impact of stroke caregiving (Gaugler, 2010) and concludes that the duration of care is not a significant predictor of stroke caregiving outcomes in quantitative studies whereas qualitative studies suggest a more dynamic process. Gaugler, like others, argues for more research and greater clarity of the concepts employed.

5.10   Managing uncertainty in life after stroke: a qualitative study of the experiences of established and new informal carers in the first three months after discharge.

Greenwood, N., Mackenzie, A., Cloud, G., Wilson, N. (2009a). International Journal of Nursing Studies, 46: 1122-1133.

5.11   Loss of autonomy, control and independence when caring: a qualitative study of informal carers of stroke survivors in the first three months after discharge.

Greenwood, N., Mackenzie, A., Cloud, G., Wilson, N. (2010) Disability & Rehabilitation, 32(2): 125–133

Since both these publications were derived from the same project and both relate to participants' experiences they are considered together. This research moved away from concepts such as patient satisfaction and focussed on overall experiences. When compared with my early patient satisfaction work, there was also a shift to an interpretive approach with less direct effort to identify outcomes obviously amenable to change. It borrowed some methods from ethnography (Hammersley & Atkinson, 1995) and looked at carers' experiences from their perspectives.

When this project started the research questions had yet to be fleshed out and since I was working full-time in the area, I was in a position to develop the research and immerse myself in it. I did most of the recruitment sitting in on multi-disciplinary team meetings and visiting the acute and rehabilitation wards to meet carers. Most potential interviewees were keen to take part but I sometimes struggled to explain qualitative research and depth interviewing to non-researchers (Greenwood, 2009). I was also responsible for the data analysis. Although I had continued to do quantitative analysis, I had not undertaken qualitative analysis or writing up qualitative research since the study with Asian patients and their carers (Greenwood et al, 2000). There was a vast amount of data but it proved a very useful experience consolidating these skills.

I mentioned the concept of 'burden' earlier (Section 2.3.2) but additional discussion is warranted here. I found that both carers and stroke survivors were frequently unhappy with the word and none spontaneously used it, except sometimes to report that stroke survivors had said they did 'not want to be a burden'. Arguably social desirability is at play here with participants unwilling to describe their cared-for person as a burden. We should also be mindful of the nature of the interview and the narrative produced. According to Tew (2008:278): 'Any narrative is, by its very nature, selective in what experience is related and what is ignored or concealed. 'Filters' may be applied even before any word is spoken or written. Some stories are perhaps too painful or difficult for people even to tell to themselves. Many stories are constructed as attempts to communicate with a real or imagined listener and so are constrained on the basis of what a person may imagine their listener might understand or be comfortable

with.' However, it is perhaps worth mentioning that our carer participants were frequently very candid about their anxieties and difficulties. Overall adopting a term carers both dislike and find questionable surely does not fit into research that should be guided by those most closely involved.

A feature of our interviews highlighted in (Greenwood et al, 2009a) was the descriptions of satisfactions and positives derived from caring offered by participants, especially over time. We found that references to satisfactions with caring increased over the three months of data collection. The most likely explanation for this is a change in carers' perceptions of their situation as it seems probable that as participants became more familiar with the interviewer, they might become more open and willing to express negative feelings.

Although there is some literature on the satisfactions of caring especially in Alzheimer's (Tarlow et al, 2004), there has been relatively little in relation to stroke carers (Pierce et al, 2007). This important area finally seems to be being addressed (e.g. Haley et al 2009) but the research is in its infancy. It appears an area worthy of much more exploration since it may help understand how carers cope in often difficult circumstances (Nolan et al, 1996). Our research suggested that those who highlighted positive aspects of their experiences earlier also described coping strategies sooner. These findings prompted further work looking at the positives or satisfactions in caring (Mackenzie & Greenwood, submitted).

Another important finding here was that some participant characteristics not habitually collected, for example, prior caring experience, may be very important to current experiences and maybe as significant (or more so) as routinely collected characteristics such as gender. Such features may be harder to measure than commonly recorded characteristics but should be investigated further if we intend to improve carer experiences.

Literature exists on changes in autonomy in people with chronic illness but it is not usually highlighted for carers. Our study (Greenwood et al, 2010) revealed that carers frequently reported reductions in autonomy which were clearly difficult for them, especially younger carers and early on in the caring role. Marked loss of autonomy is perhaps unsurprising in these groups for several reasons. New carers may require huge restructuring of their lives and younger carers in particular are likely to have other significant responsibilities such as paid employment or childcare. This increases the potential for reductions in autonomy. Our recent meta-ethnographic review Greenwood & Mackenzie (2010a) highlights the significance of biographical disruption (Bury, 1982; 1991) suffered by carers which we suggested is probably greater for younger carers and those with additional responsibilities.

So far these publications have received few citations but I was contacted in May 2010 by the USA National Stroke Association who intends to use both these publications in new education programs for caregivers of stroke survivors.

5.12 Caring for stroke survivors: meta-ethnographic review of qualitative literature.
Greenwood, N., Mackenzie, A. (2010) Maturitas, 66: 268-276.

This is my latest review and in many ways would have been impossible without the other publications. I was invited to do a review of stroke carer research by the editor of Maturitas and I agreed on the basis that it would be both more recent than the other reviews and would use a different approach. I opted to use meta-ethnography (Noblit & Hare, 1988; Britten et al 2002; Campbell et al, 2003) because it appeared to take synthesis further. It is my most highly developed synthesis and was greatly helped by other reviews and publications in the area. This method encourages linking together concepts often appearing in isolation and putting them into meaningful theoretical models. It provided a fuller, broader picture of the impact of caring for stroke survivors than my earlier reviews and I hope will add to discussion in the area.

6   Conclusions

Putting together this commentary has provided an opportunity to reflect on the research I have undertaken and the methods I adopted. It has allowed me to take a different reflexive and sometimes critical perspective but also highlighted the skills I have gained and how I have developed as a researcher. It has been an interesting process because although discussion and conclusion sections in publications superficially offer this opportunity, in reality journal word count restrictions and immediacy to the research itself, often limit the scope for reflection. Writing this commentary has been reassuring because, in most cases, if given the same research briefs again, I would adopt similar approaches. However, the introduction of tighter research governance over the last decade (Gerrish & Guillaume, 2006; Dixon Woods & Yeung, 2010) means that perhaps it would have been more difficult to undertake some of the studies in the same manner now. It would undoubtedly have required longer contracts because of the time it currently takes to progress through research governance.

Writing this commentary has brought into focus the themes running through my research and has highlighted both some methodological questions and the impact of being a contract researcher on research. I hope I have also demonstrated how I have added to the knowledge base relating to experiences of health services in disadvantaged groups. Going back over the research has also allowed me to examine the impact of my research in a variety of contexts. Some studies have been cited frequently in peer reviewed publications as shown by Google Scholar citations and in some instances, the suggestions or conclusions have been followed up in later research. Others have been seldom cited in academic journals but have been used by organisations such as Mind or Alcohol Concern.

The research I have undertaken has all been intended to understand, describe and improve the experiences of those using health services. It is difficult to know whether it has resulted in significant improvements for patients. Certainly some suggestions from the studies have been put in place but perhaps one of my greatest compliments came from a stroke consultant who said that my research with carers had influenced his clinical practice. He now approaches carers differently and asks specific questions identified from the research. I found this very satisfying.

Being involved in so many varied projects means that I have both increased and improved my research skills and am able to use these in current and future research. I now have greater confidence in adopting mixed methods and do so consciously rather than purely for pragmatic reasons as I once did. Similarly I place greater store in investigating and responding to patient and carer experiences. I still believe that better understanding of the impact of user involvement

in research is required and that it should not be incorporated in research simply as a knee jerk response to government policy but I now regard it as essential to health services research.

In a different fashion I have also benefitted from my research participants. I have been repeatedly humbled by their wisdom and positive approaches often in very difficult circumstances. It is unlikely that I would have had such experiences if I had not been employed as a contract researcher on such a variety of studies. I am grateful to them and to those who employed me and worked with me over the last decade or so.

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Appendix A: References for included publications

Copies of these publications are contained in Volume II.

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Appendix B: References for publications referred to but not included

Copies of these publications are contained in Volume II.

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Appendix C: Justification of shared authorship

All the publications presented in this thesis are jointly authored. There are two reasons for this. Firstly, in all cases I was the contract researcher employed to do the research by permanent researchers who had gained outside funding. Recognition of their contribution was therefore essential. Secondly, I am convinced the research benefitted from multiple inputs, often from a variety of disciplines, and although some members of the publication teams may have spent little time working on the projects, they provided important insights. A good example is Dr Geoff Cloud, a stroke consultant at St George's Hospital who was invaluable to the carer research. Not only did he offer continuous support and facilitated recruitment but at times his local knowledge and clinical background provided perceptions in interpreting the data that I alone would have been unable to provide.

In most of the publications presented here I am the first author. On the two occasions where I am second author (Farmer and Greenwood, 2001; Singh et al, 2007) the research resulted in full reports and I agreed to be first author on the reports and second on the publications. For both studies, the publications arose directly from the reports.

Full details of my contributions to individual publications are provided in Appendix D.

Appendix D: Table of the roles played by the authors

The specific roles taken by the candidate and other authors are outlined under each publication's reference. In all cases the candidate was the primary researcher and the co-authors read and commented on the papers or reports.

Publication	Input from the authors
1. Greenwood, Key, Burns, Bristow & Sedgwick (1999)	The overall aim of this study was to explore patient experience on acute psychiatric wards. This general aim allowed considerable scope in choosing both the specific research questions and research methods. The candidate was responsible for identifying the research questions and key areas of inquiry, literature searching, selecting the method, questionnaire design (including which elements of patient experience to investigate), piloting, recruitment, data collection and the statistical analyses. She interpreted the findings, and identified the key findings and wrote both the report and the ensuing publication. The other authors acted primarily as advisers to the project and Philip Sedgwick guided the multiple regression analysis. (Estimation of input 85%)
2. Greenwood, Hussain, Burns & Raphael (2000)	The candidate was responsible for the qualitative data analysis including identifying the themes and issues important to participants and for writing the overall report and the publication. The research was originally led by Tom Burns and Frances Raphael whilst Feryad Hussain collected the data but both Dr Raphael and Ms Hussain left their posts soon after the data collection and the candidate took over writing up the project. (Estimation of input 65%)
3. Greenwood & Farmer, (2000)	This project was funded as a service evaluation but the candidate was able to expand it to include a publishable research element investigating GPs' attitudes to problem drinkers. She was responsible for developing the protocol, specifying and focussing the research questions, determining the areas for investigation, literature searching, research design, constructing and piloting the questionnaires, recruiting participants, collecting and analysing the data, writing the overall report and identifying the key findings for the paper. Both this paper (number 3) and paper number 4 were derived from the report. The candidate led the writing for publication 3. (Estimation of input 90%)
4. Farmer & Greenwood (2001)	For publication 4 Roger Farmer led on the writing. (Estimation of input 85%)
5. Greenwood & Bithell (2005)	Christine Bithell gained funding to investigate the under-representation of minority ethnic students on allied health profession degree courses. From this general brief, the candidate was responsible for refining and focussing the research questions, writing the protocol, the research design, formulation of the interview schedule and questionnaires and managing the data collection and analysis. She wrote the report and the publications arising from it. (Estimation of input 95%)
6. Greenwood, Singh, Churchill (2006) (Report)	This research was funded by the Department of Health who wanted a very specific issue relating to the Mental Health Act (1983) investigated. Their primary interest was identifying the varying compulsory admission rates for different ethnic groups but we were able to widen the focus to for example examine critically the explanations offered by authors for the excess of detentions of Black patients. The candidate was responsible for fleshing out the protocol,
7. Singh, Greenwood, White , Churchill (2007)	

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	reading the papers identified by the database searches, selecting those that fitted the inclusion criteria and the data extraction. Swaran Singh independently repeated the selection process as is usual in systematic reviews. Sarah White carried out the meta-analysis. The candidate identified the key findings, analysed explanations for detention rates offered by authors and wrote the report (6) (Estimation of input 85%). The candidate also drafted publication 7 which arose directly from the report but Swaran Singh was responsible for the final submission. (Estimation of input 75%)
8. Greenwood, Mackenzie, Cloud, Wilson (2008)	The idea to do review (8) was the candidate's who had identified a gap in the literature. The choice of search terms, literature searching, selection of papers for inclusion, construction of the quality rating scale and identification of key points to extract from the papers were her responsibility. Ann Mackenzie's role was to repeat the selection process as is usual in such reviews. Collection of data from the papers was undertaken by the candidate and checked by Nikki
9. Greenwood, Mackenzie, Cloud, Wilson (2009)	Wilson. This publication was written by the candidate. Geoff Cloud was included because he commented on the earlier review process and on the final papers. In publication 8 we had excluded qualitative research and on the advice of the Editor of Disability & Rehabilitation the candidate decided to undertake a further systematic review (9) of the available qualitative research. The selection of papers for inclusion, construction of the quality rating scale and identification of key points to extract from the papers were her responsibility. Ann Mackenzie's role was to repeat the selection process. Collection of data from the papers was undertaken by the candidate and checked by Nikki Wilson. The publication was written by the candidate. Geoff Cloud was included because he commented on the earlier review process and on the final paper. (Estimation of input 85% for both reviews)
10. Greenwood, Mackenzie, Wilson, Cloud (2009)	The candidate was responsible for specifying the issues for investigation, the design of the research and topic guide used in the depth interviews using ideas from the above reviews (publications 8 and 9). She recruited the participants and undertook about 70% of the interviews whilst Nikki Wilson carried out the remainder. The candidate led the qualitative analysis which was then repeated by Ann Mackenzie. The candidate wrote the publications. Geoff Cloud had an advisory role and commented on the research throughout. (Estimation of input 85% for both publications)
11. Greenwood, Mackenzie, Cloud, Wilson (2010)	
12. Greenwood & Mackenzie (2010)	The candidate was invited to do this review by the editor of the journal Maturitas. She was responsible for the approach adopted, literature searching, selection of articles, data selection and writing the article. Ann Mackenzie checked the article selection for the review and data collected and read and approved the publication. (Estimation of input 90%).

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