

Research Priorities for Service User and Carer-Centred Mental Health Services

A synthesis of the literature and policy documents

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Report for the National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO)

July 2006

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Executive Summary

Will this need revising in view of your changes?

This report describes a literature synthesis to identify research priorities for patient and carer-centred mental health services that was commissioned by the National Coordinating Centre for Service Delivery and Organisation (NCCSDO) in January 2005. The review considered English Language literature, excluding papers from the United States of America, on patient and carer-centred services between January 2000 and May 2006.

Aims

- To provide a synthesis of existing work on patient and carer-centred services in mental health and social care, and
- To identify research priorities in mental health and social care.

Objectives

- To review relevant published and grey literatures,
- To judge the relevance of the literature available using a critical appraisal framework,
- To summarise the results obtained and search for strong themes that emerge from the literature,
- to provide a detailed report that provides a map of existing documents in the area and identify areas and priorities for future research, and
- To produce a report and publish at least one paper on the findings in a peer reviewed journal.

Methods

We drew on established methods for conducting reviews and adapted these due to the broad scope of the literature. We set broad inclusion criteria and we searched only English language papers between January 2000 and May 2006. Bibliographic data bases were searched to find published literature and the web pages of a range of organisations were searched to find grey literature. The literature was assessed using a critical appraisal framework.

To ensure reliability and minimise the risk of errors of judgment, three reviewers independently selected for relevance a sample of citations found. Any disagreements between reviewers were discussed and selection criteria were revised accordingly. The Initial level of agreement on inclusion between researchers was 72% and with discussions and looking again at the criteria for inclusion agreement reached was 98%.

Findings

The literature contained many examples of how to involve service users and carers in service development and planning, but there was little focus on how to develop patient and carer-centred services. Barriers to service user and carer involvement

have been identified and there were suggestions for ways to increase service user and carer involvement. There was no evidence on how these activities or foci could translate into patient and carer-centred services.

Research Priorities

The research priorities have been organised thematically rather than rank ordering.

Patient - and carer centred care

Research is needed to identify:

- what patient and carer-centred care means,
- what its key dimensions are,
- which interventions constitutes patient and carer-centred care,
- reliable and appropriate tools/outcome measures to assess the effects of interventions to promote patient and carer-centred care, and
- best ways of training professionals to adopt patient and carer-centred approaches in their practice.

Service user involvement

Research is needed to:

- evaluate how service user involvement can be translated into patient-centred care,
- evaluate the role of the care programme approach in delivering patient and carer-centred care, and
- evaluate to whether participatory approaches, such as action research and observational studies contribute to the knowledge base on patient and carer-centred mental health services.

Carer-centred care, carer involvement and support

Research is needed to:

- What carer-centred care means,
- What its key dimensions are,
- Which interventions constitutes carer-centred care,
- evaluate how carer involvement can be improved and how this can be translated into carer-centred services,
- Study the long term impact of caring,
- Identify the needs of specific groups of carers such as young carers, carers from BME communities, carers in same-sex relationships and those who support someone with a dual diagnosis, and
- Differentiate between the effectiveness of interventions for specific groups of carers, e.g., spouse and non spouse carers, female and male carers, etc.

Marginalised groups

Research is needed to:

- Study the experiences of people with learning disabilities of mental health services,
- Examine to what extent person-centred planning contributes to patient and carer-centred services,
- Study the impact of different service models to meet the needs of people with dual diagnosis,
- Set up clinical trails to identify the most important ingredients of successful therapy for people with dual diagnosis,

- Improve the evidence base on practice, clinical outcomes and effectiveness of services for children and young people,
- Understand how to best meet the needs of particular groups of young people, such young people from BME communities and young offenders,
- Determine the effectiveness of treatment interventions in women,
- Service evaluation and research should include gender as a key variable in analysis and presentation.
- Examine progress in reducing the inequalities and disparities in services for BME communities, and
- Study the extent of psychological need in refugee and asylum seeker communities and to determine the most desirable treatment approaches.

General Priorities

Research is needed to:

- Explore how a more holistic model of mental illness could promote patient and carer-centred services,
- Examine how we can increase the psychological components of care,
- Evaluate the effectiveness of acute services and the efficacy of user-led alternatives to inpatient care
- Evaluate effectiveness of behavioural interventions, e.g., for schizophrenia, and depression,
- Study the efficacy of support interventions for socially isolated and vulnerable groups;
- Explore the most effective ways of improving access to appropriate care, and
- Evaluate the efficacy of mental health promotion

We conclude that this literature synthesis has identified a set of research priorities that could add significantly to the knowledge base on patient and carer-centred mental health services.

1 Introduction

This report describes a literature synthesis that was commissioned by the National Coordinating Centre for Service Delivery and Organisation (NCCSDO) in January 2005. The review considered English Language literature, excluding papers from the United States of America, on patient and carer-centred services between January 2000 and May 2006. We want to make it clear at the outset that this review was far more difficult than anticipated. The review was intended to cover all age groups (including marginalised groups), all service types and diagnostic categories. This required that we needed to keep the scope of the review relatively broad. However, this meant that we found a large, but disparate body of literature which made it difficult to assess the quality of the evidence. Instead we searched for relevance to the themes of patient and carer-centred care and only considered papers and policy documents that specifically address what we considered to be components or elements of these themes. The purpose of the literature synthesis was to identify research priorities in policy literature, peer reviewed journals, published reports and research recommendations in NICE guidelines.

1.1 Background

Patient and carer-centred care is central to the Government's health and social care modernisation agenda (Department of Health, 2004a). A variety of policy initiatives have been introduced to situate the interests and concerns of users of mental health services and their families and carers at the core of service development, planning and delivery. The NHS and Community Care Act 1990 (Department of Health, 1990), for example, stressed the need for patients to be involved in the care planning process. More pertinent to mental health and social care, the National Service Framework for Mental Health (Department of Health, 1999) specifically provided standards to guide the development and delivery of patient and carer-centred services. Policy guidance pertaining to user involvement in research has also been issued by the Department of Health (Department of Health, 2001a). National Service Frameworks (NSF) relating to other groups such as the NSF for Older people (DOH, 2001b) and the NSF for Children (DOH, 2004b) and Valuing People (DOH, 2001c) all embrace and promote patient-centeredness. The needs and interests of families and carers have also been pushed to the fore of the policy agenda and there is now legislation to ensure that their needs receive prominence in the provision of mental health care (DOH, 2000a). The Government's choice agenda underpins much of the reforms of the NHS that is currently taking place under the banner of "Creating a Patient-led NHS (DOH, 2003a)

There exists a large body of literature advocating the importance of the consumer perspective in mental health (Noble et al. 1999). The views of families and carers have also been considered important (Brand 2001). By incorporating the views of users of mental health services Beeforth & Wood (2001) identified ten user priorities for the development of mental health services ranging from access to information to an integrated system with continuity of care. Reports such as Rose (2001) highlights

user perspectives on care delivery and clinical issues, recommending the involvement of users in training mental health professionals. However, there is little evidence of initiatives to establish research priorities for patient and carer-centred services. Thornicroft, et al. (2002) carried out a study to identify the research priorities of mental health service users in a locality in South London. They found that the top priority for people, who have experience of using mental health services, was user involvement in all stages of the research process. Other priorities included discrimination and abuse, advocacy, art therapy, the value of choice in treatment, complimentary medicine and therapies, the effects of providing information to service users, reflective measures to reduce discrimination and the characteristics of treatment settings such as inpatient wards in relation to effective treatment and care. Lomas et al (2003) in a listening exercise for setting research priorities for health services in two countries, England and Canada, found that the themes emerging from the English exercise were: organising health services around patient's needs, user involvement, and continuity of care, coordination/integration across organisations, workforce issues and so forth.

These categories were used as a guideline to search the literature and examine the current evidence in relation to these themes. This literature examined the current evidence base on patient and carer-centred services. It specifically identifies:

- What is currently known about such services?
- How they have developed?
- What evaluations have been carried out to assess effectiveness?
- The gaps in existing knowledge.

Are these bullet points still applicable in terms of how the literature was ultimately synthesised?

The insights gained from the literature were used to define themes and priorities for future research in mental health and social care and to recommend strategies for achieving this. The Sainsbury Centre for Mental Health research team adopted a citizen involvement framework (Department of Health, 2004a) to help to reflect as far as possible the values and assumptions of all stakeholders, i.e., patients, families and carers, and all mental health professionals. A citizen involvement framework is based on the premise that services should be equitable and fair and that it is the democratic right of individuals to be involved in assessing their level of need and decisions about meeting those needs. We believe that this is at the heart of patient and carer-centred services. We therefore examined to what extent the published and grey literatures (including relevant policies) reflect this philosophy. Following the lead of Lomas, et al (2003) we viewed this literature review as a technical exercise that can only answer questions related to the capacity of the research community or to service delivery and organisation, rather than to the direct improvement of the nation's mental health.

1.2 Aims & Objectives

Aims

- To provide a synthesis of existing work on patient and carer-centred services in mental health and social care, and

- To identify research priorities in mental health and social care.

Objectives

- To review relevant published and grey literatures,
- To judge the relevance of the literature available using a critical appraisal framework,
- To summarise the results obtained and search for strong themes that emerge from the literature,
- to provide a detailed report that provides a map of existing documents in the area and identify areas and priorities for future research, and
- To produce a report and publish at least one paper on the findings in a peer reviewed journal.

The remainder of this report describes the methodology that was adopted to conduct the review; presents the results from the literature searches and analysis and identifies the research priorities that were derived from the literature. In the reference section we include all the literature consulted and append summaries of the literature and documents that were included in the review in tabular form.

2 Methods

The literature in the area of patient and carer-centred care is large and diverse. Rose et al (2002) suggest that when a body of literature is large, it poses certain challenges. For example, the data from the studies may either be too sparse or too heterogeneous to be sensibly combined. The data may therefore not lend itself to quantitative synthesis, that is, using statistical techniques to combine and compare results of included studies as with a meta-analysis. To address these issues a narrative thematic analysis approach described by Mays et al (2001) was used to perform the literature synthesis.

The Centre for Reviews and Dissemination (NHSCR, 2001) has produced guidelines for systematic reviews. These normally consist of:

- Question formulation
- Searching the literature
- Establishing relevance
- Relevance and quality assessment
- Data extraction and synthesis
- Producing the report
- Peer review of the report
- Presentation and dissemination of the report

We followed as far as was possible these guidelines as the methodology to structure the literature review and synthesis.

2.1 The research questions

What is the available literature in terms of research priorities and developments of mental health services in general and in particular patient and carer-centred services in mental health? How are mental health services defined or conceptualised in relation to patient and care-centred services? What research has been done to promote patient and carer-centred services? What gaps exist in the research and policy literature in mental health and social care?

2.2 Search Strategy

Papers for inclusion were identified by searching the following electronic data bases: ASSIA, Embase, CINAHL, MEDLINE, Psychinfo, Pubmed, The Cochrane Library and the Centre for Reviews and Dissemination. The search was limited to papers between January 2000 and May 2006. Search strategies were defined with the assistance of an experienced Librarian. The searches were organised around the topics identified by Lomas et al. (2003) and Thornicroft et al. (2001). We included text word synonyms for each of these headings. The review group leader (FK) the Researcher (KF) and the head of research at SCMH (CS) independently reviewed the captured titles and abstracts and marked all those that appeared relevant. Full articles were

retrieved for detailed review and evaluation. Anticipating that electronic searches may miss some articles and to ensure completeness we checked the citations of papers identified from electronic databases; and, consulted key informants and experts in the field to access other references and grey literature. We searched the Databases of the Department of Health, the National Institute for Mental Health England (NIMHE), National Institute for Clinical Excellence (NICE), the Social Care Institute for Excellence (SCIE), Mental Health Foundation, MIND, Rethink, MACA, SDO, SCMH and Involve for policy related documents. Other grey literature was accessed through SIGLE (System for Information on Grey Literature), NTIS (National Technical Information Services), Health management Information Consortium CD-ROM and the British National Bibliography for Report Literature. We searched the National Research Register for ongoing research studies relevant to this area. We used EndNote (a bibliographic software package) to manage the references which were included in the review. Finding and searching literature was particularly difficult due to the broad scope of the review. We attempted to address the breadth of research across different sectors, professional boundaries, different interest groups, and a range of client groups. The search terms were therefore kept deliberately broad. We did a search on subject headings first followed by a free text search. The following terms were used:

- Mental health services and patients,
- Mental health services and carers,
- Mental health services and ethnic minorities,
- Mental health services for people in prison,
- Mental health services and asylum seekers,
- Mental health and homeless people,
- Mental health services and learning disabilities,
- Mental health services and physical disabilities,
- Mental health services and people who are excluded,
- Mental health services and older people,
- Mental health services and people younger than working age,
- People with mental health problems and choice,
- People with learning disabilities and choice,
- Patient-centred/services/mental health services,
- Carer-centred/ services/mental health services,
- Service users/mental health/mental illness,
- Carers/ mental health/mental illness,
- Service user involvement/ mental health, and
- Carer involvement/ mental health

2.3 Study Selection

The criteria for including and excluding citations were kept deliberately broad, to avoid the risk of excluding papers reflecting the wide range of services and populations with mental health problems, and similar to those specified by Alborz et al. (2004). These included:

- People with mental health problems from a range of groups including children, older people, learning disabilities, substance misuse, minority and ethnic groups, women, and hard to reach populations such as the homeless, refugees, asylum seekers, travellers, etc.

- Relevance to mental health and social care services
- Restricted to countries with similar health care services to the UK, e.g. Canada, Australia
- English language papers only
- Any study design
- Papers between 2000 and May 2006.

All potentially relevant citations were identified after liberal screening of the electronic search outcomes. We recorded all the citations that were excluded and the reasons for this. We are aware that excluding US and non-english literature from the review may have introduced some bias in the study. Our assumption was that the US health care system was too different and it would have been difficult to equate with that of the UK. It may be useful in future to develop comparative reviews to explore what the UK can learn from developments in patient and carer-centred care in other contexts such as the US.

These selection criteria yielded a large number of references, so in order to reduce ambiguity the team in discussions and review decided to establish boundaries for what was included and excluded. We decided to specifically focus on what the literature told us about a) patient and carer-centred services; b) service user and carer involvement; c) what attempts or suggestions have been made to achieve service user and carer involvement and to what extent they have been evaluated; and d) what new research we need to promote and develop patient and carer-centred services. We also identified key issues for marginalised groups, i.e., those groups whose needs are not always met by mental health services. This produced a smaller and more focused data set for review and analysis. Our rationale for this narrower focus was premised on the assumption that it is necessary to know what constitutes patient and carer-centred care in order to measure it and set research priorities for achieving such care.

2.4 Relevance and Quality Assessment/evaluation

There were two stages to go through the literature before it was included for review. First, the titles of citations were checked for potential relevance to the review questions. Where titles proved inadequate, the abstracts were then examined. Although Hartley (1995) points out the quality of the latter can vary and may not assist the user in judging relevance. Second, where the title and or abstract indicated that it related broadly to patient and carer centred services the document was obtained. Many of the references were not relevant, but were retrieved due to the broad nature of the search. A final set of references for review was compiled by a process of filtering in accordance with the inclusion criteria as described above. The literature was assessed using a critical appraisal framework. According to Hill & Spittelhouse (accessed 12 October 2004 on (www.evidence-basedmedicine.co.uk)) critical appraisal is: "the process of systematically examining research evidence to assess its validity, results and relevance before using it to inform a decision." Given our theoretical framework and that we were reviewing strategies for developing patient and carer-centred services, the organisational cultures that are conducive to such services and the complexity of policy initiatives we examined relevant literature of all study types, giving equal emphasis to each design, particularly studies conducted from a service user perspective. Due to the paucity of literature in this

area and the inclusion of policy documents and grey literature, we assessed the papers for relevance and not for quality.

All studies selected were reviewed using an adapted version of a study evaluation tool by the Health Care Practice Research and Development Unit, University of Salford (2001). This tool provided a brief and efficient method for assessing the relevance of the study and the parts relevant for data extraction. The evaluation tool was designed to incorporate the diverse nature of health care research and differing study methodology. Once designated, relevant full papers were obtained and assessed for relevance. A database (using Microsoft Access) was set up to record and manage the information gathered using the evaluation tool as a template.

To ensure reliability and minimise the risk of errors of judgment, three reviewers independently selected for relevance a sample of citations found. Any disagreements between reviewers were discussed and selection criteria were revised accordingly. The Initial level of agreement on inclusion between researchers was 72% and with discussions and looking again at the criteria for inclusion agreement reached was 98%. We found that the literature was ambiguous and a great deal of our initial discussions and thoughts included establishing the boundaries for what was included and excluded.

2.5 Data extraction

The study evaluation tool was used to extract essential information concerning the citations details, such as authors, journal or report, publication details, reviewer etc. Specific information was recorded in terms of the:

- Types of mental disorder being investigated,
- The aims of the research or policy, i.e., is it prevention, service evaluation, genetics, prevalence, risk factors, pathways to care, etc.,
- Participant type and setting where research was carried out,
- The inclusion of particular groups, e.g. people from minority ethnic groups, younger and older populations, hard to reach populations (substance misusers, the homeless, refugees, etc.), lesbians and gay men, people with disabilities, etc.,
- Study methodology, any interventions, outcomes, results and their validity/reliability, etc
- Recommendations for future research: These have been summarised to inform the research priorities for patient and carer-centred services.

We specifically focused on identifying the more substantive issues of patient and carer-centred themes by considering discussions of user/carers centred services, recommendations for achieving patient and carer-centred services, evaluations and recommendations for service user and carer involvement, involvement of service user and carers in research, and recommendations for future research.

2.6 Data synthesis and analysis

We found that drawing together literature from a wide range of sources and different study designs proved a challenging task. Our starting point was to narrow the

literature down by using principles of a narrative thematic approach, bearing in mind that there is no single method for synthesising literature that has been drawn from a wide range of sources (Mays, 2001). A narrative thematic analysis allows for different types of evidence to be reviewed. This iterative process was used to organise the literature into 2 broad categories, i.e., those pertaining to patient-centred care and those pertaining to carer-centred care. These categories were further sub-divided by age group and marginalised groups. The recommendations for future research or any research gaps identified were summarised. The findings were then related to the key questions for the literature synthesis.

The framework for the analysis was to examine what the available literature contained about patient and care-centred services, what suggestions have been made to promote and achieve patient and care-centred services, and what research is needed to promote this agenda. This process involved narrative summaries of the aims of the study, the key findings and recommendations for future research to familiarise ourselves with the data. The recommendations for future research and gaps in the literature were key factors in developing the research priorities. As mentioned earlier, the data was divided into broad categories, i.e., patient-centred care/services; carer-centred care/services; types of services; age categories and marginalised groups. We then searched for data that captured something important in relation to the research questions as outlined in section 2.1. The next step in the process was to search for common themes in the data. The specifics of the themes were refined and finally related back to the research questions to produce a set of research priorities.

Data synthesis of the research recommendations listed in policy documents or other relevant grey literature was performed, and given equal weighting to the data drawn from research papers. Recommendations for service developments gathered from guidelines, such as those produced by NICE and technology appraisals were considered in the data synthesis. Where possible, we also examined to what extent recommendations for future research have already been implemented and will highlight this throughout the presentation of the results.

3 Search results

The results in this section will be organised and presented around the research questions identified earlier. In excess of 1780 references were found initially, but on closer scrutiny, a very small number was selected for inclusion in the literature synthesis. (See table 1 below for a detailed breakdown). It is natural that where search terms are broad any search will yield a large number of references. When we were faced with such a large body of literature we realised the near impossibility of the task, i.e., to include all of mental health, all types of services and settings, all age groups and marginalized groups. A revision of the inclusion criteria enabled us to achieve a more manageable set of references. The final selection included original research papers, review papers, discussion papers, research reports and policy documents and clinical guidelines.

The literature contained many examples of how to involve service users and carers in service development and planning, but there was little focus on how to develop patient and carer-centred services. Barriers to service user and carer involvement have been identified and there were suggestions for ways to increase service user and carer involvement. There was no evidence on how these activities or foci could translate into patient and carer-centred services.

Table 1 – Search Results

Document Source	Met criteria	basic	Selected for screening	for	Included for synthesis	for
Electronic data bases	400		135		31	
Department of Health	200		78		8	
Social Care Institute for Excellence	41		20		0	
NIMHE	94		12		4	
Cochrane Library	75		16		4	
Centre for Research & Dissemination	14		5		1	
Involve	23		13		1	
SDO	6		6		6	
Mental Health Foundation	2		2		1	
Expert Panel Members	7		7		1	
MIND	1		1		0	
Rethink	3		3		3	
Young Minds	1		1		3	
Royal College of Psychiatrists	1		1		1	
Chartered Society of Physiotherapy	1		1		1	
NICE	5		4		3	
Sainsbury Centre for Mental Health	3		3		3	
Total	867		302		60	

Original research papers addressed the following topics:

- Patient-centred outcomes,
- Satisfaction surveys,

- Evaluation studies to measure the effectiveness of interventions,
- Surveys to investigate the needs of particular groups, and
- Clinical trials to compare interventions

The majority of studies focussed on people with severe mental health problems. Study methodologies included survey designs, evaluation studies and content analysis of case notes. In terms of participant type, studies included service users (N= 7), carers (N=3), service users and carers (N =3), children and adolescents (N =2), mental health professionals (N =3), and two studies focused on refugees and African-Caribbean communities respectively. Where settings were identified, studies focused on inpatient settings, children and adolescent mental health services and community mental health teams. Where types of services were identified these focused on early intervention, assertive outreach and interventions for carers.

From the policy literature we reviewed policy guidance on suicide prevention, inpatient services, families and carers of people with mental health problems, older people with mental health problems, gender, Black and minority ethnic groups (BME), and children and young people. In terms of clinical guidelines we reviewed NICE guidelines on Schizophrenia, Depression and Depression in Young People.

The over-riding aim in identifying the priorities for research was to concentrate on those that could be useful in promoting patient and carer-centred mental health services. A key finding was that we did not find any studies that addressed prevention, and there was a lack of systematic reviews and a lack of clinical trials. This finding is supportive of the findings in the strategic review of mental health referred to in section 3.1 and certainly illustrates the need for the research community to respond to this.

To set the context for presenting the priorities we review priorities identified in previous research priority setting exercises and those contained in policy documents. We then proceed to give an overview of the research papers and reports included in the synthesis before presenting the research priorities.

3.1 Findings from Previous Research Priority Setting Exercises

As part of the modernisation agenda there is a commitment by the DOH to develop a programme of research to support the implementation of the National Service Framework for Mental Health (NSMH). In order to achieve this, a review of the effectiveness of mental health services was commissioned (DOH, 2001) and a strategic review of research and development in mental health was carried out (DOH, 2002). It was also envisaged that research would be carried out and harnessed by the establishment of the Mental Health Research Network (MHRN) with specific subject interests. We report here on the findings from the strategic review of research, the review of effectiveness on mental health services and 2 scoping exercises that have been carried out by MHRN subgroups. The latter were the only scoping exercises that have been carried out in the timeframe of this study.

The Department of Health (2002) conducted a strategic review of research and development in mental health which identified the lack of systematic reviews in

mental health as a matter for concern. The review concluded that there is a need for more research related to mental health promotion, primary care, access to services, services to support carers and suicide. The review also recommended research which is particularly focused on issues relating to black and minority groups and to the service needs of women. A service user panel contributed to this review and recommended that:

- the research agenda needed to be more proactive in relation to government policy,
- a more holistic model of mental illness be researched rather than solely the medical model,
- research should always include user-defined outcomes,
- user-led alternatives to hospital care should be evaluated,
- research priorities should address the issues and needs of women and black and minority ethnic communities, and
- that service users should be supported to contribute at all stages of the research process.

A scoping review of the effectiveness of mental health services (CRD, 2000) identified that there are a range of service interventions that have not been addressed by systematic views, i.e., interventions to reduce stigma, intervention within hospital settings and interventions for carers. It recommended that we need further research on outcome measures such as service user networks, user and carer satisfaction, social relationships and quality of life and that these should be incorporated into future systematic reviews and primary research.

There has been a number of research priority setting exercises commissioned by the NIMHE Mental Health Research Network, i.e., for older people including dementias and for young people.

The recommendations that relate to patient and carer-centred services from these will be reported briefly.

A scoping exercise was carried out to identify research priorities for the mental health of older people including the dementias (Willis et al, 2005). Two key priorities for research were identified: research is needed to develop and test psychological interventions for people with dementia and their carers; and research to study the effects of interventions for dementia on carers.

Two key priorities for research were identified: research is needed to develop and test psychological interventions for people with dementia and their carers; and research to study the effects of interventions for dementia on carers.

In relation to children and young people McCombie & Chilvers (2005) carried out a consultation exercise with Child and Adolescent Mental Health Services professionals to identify research priorities. The following research priorities were identified: a) there is a need for research into population-based approaches to mental health promotion and intervention; b) a need for research into how to increase the psychological components of care; c) how to best engage with the wider population, including cultural competencies for health promotion initiatives and services, differences in health seeking behaviour of different subsets of the population; d) how to overcome barriers to multi-agency collaborative working, e.g., in assessment, planning, intervention and training; e) access to specialist mental health services; f) transition from CAMHS to Adult Mental Health Services; and g) developing the evidence base about extending efficacious treatments and interventions into real-world practice. We consider recommendations a, d, e & g to be the most relevant to

the themes of patient and carer-centred services. McCombie & Chilvers (2005) however urge that these recommendations should not be considered as representative of all stakeholders and should therefore be considered alongside other consultations with relevant stakeholder groups.

3.1.1 Priorities from the Policy Context

As part of the Government's vision for mental health care and its modernisation agenda, there have been a number of policy developments and initiatives to build evidence-based policy. Policy documents relevant to the government's research and development strategy for the NSF were reviewed to identify research priorities specific to patient and carer-centred services. We found a number of research recommendations, but they were often more generally about the need to increasing our knowledge about certain disorders and/or understanding the needs of certain groups of individuals, rather than specifically about research to inform or develop patient and carer-centred services. The policies that will be reviewed here (presented chronologically) relate to suicide prevention, acute inpatient care, services for carers of people with mental health problems, services for women, services for black and minority ethnic communities, services for older people and services for children.

Suicide Prevention

The National Suicide Prevention Strategy aims to support the Department of Health's target for reducing the death rate from suicide by at least 20% by 2010. The strategy seeks to reduce the risk in key groups, promote mental well-being in the wider population, to reduce the availability and lethality of suicide measures, improve reporting of suicidal behaviour in the media, and to promote research on suicide and suicide prevention (DOH, 2001). In relation to research the strategy identified priorities on a) the need for detailed studies of high risk groups from which conclusions can be drawn for prevention, and b) the need for intervention studies with more common outcomes that will act as 'proxy' measures for suicide, e.g., non-fatal deliberate self-harm. These recommendations do not address the themes of patient or carer-centredness directly, but we believe research in these areas could throw light on the interventions that may contribute to the development of patient and carer-centred services.

Inpatient Services

Mental Health Policy Guidance (DOH, 2002) on acute inpatient provision aims to assist the reorganisation of inpatient services to adequately reflect the value that underpins all mental health policy. The guidance observed a dearth of mental health studies relevant to inpatient care and recommended an urgent need to commission research and evaluation on acute service effectiveness in the context of the NSF for Mental Health (1999) and the NHS Plan (2000). A report that reviews the NSF for Mental Health (DOH, 2004) found that there is now a programme

of research commissioned by the SDO. A number of studies are in progress on alternatives to admission, ward observation, inpatient care of young people and staff morale. The findings of these studies were not available at the time of this literature synthesis.

Families and Carers

Standard 6 of the NSFMH make it clear that mental health services must address the needs of carers to ensure the development of modern mental health services. The Carers and Disabled Children's Act 2000 established and strengthened the right of carers to an assessment of their needs in relation to supporting and sustaining their role where they provide substantial care on a regular basis. The DOH issued further guidance for developing Services for Carers and families of people with Mental Illness (DOH, 2002). This guidance suggested that there was a lack of clear evidence to support the effectiveness of any specific service configuration for carers of people with mental health problems. A further suggestion was that the impact and success of carer support services should be evaluated and that carers should be fully involved in this process.

Older People with Mental Health Problems

Standard 7 of the NSF for Older People focuses on the provision of evidence-based mental health services for older people and on promoting integrated services that provide early diagnosis, treatment and support for older people and their carers. The NSF outlines a research strategy for older people aimed at supporting research that will reduce disability and the need for long term care. In relation to the theme of patient-centred services the strategy aims to support research that will inform the choices of individual users of health and social care services and to provide those who deploy health and social care services with knowledge about the most effective and equitable means of meeting those choices. In terms of research priorities related to patient and carer-centred care it identifies the need for research to focus on outcomes, and user and carer perspectives.

Gender

Policy developments in relation to women such as the "Mainstreaming Gender Strategy" (DOH, 2002) suggested that gender should be a key study variable to achieve a better understanding of the differences in the mental ill health of women and men. It has been recommended that research is needed to understand how these differences inform the development of appropriate mental health care for men and women. More specifically, it recommended that further research is needed to determine the effectiveness of interventions for both men and women and how they respond to different treatment interventions.

BME Groups

The needs and issues for BME communities have received a great deal of attention in the literature, yet there is a lack evidence to illustrate how to best meet the needs of these groups. The concerns and needs of BME communities have been well documented (CHAI, 2005; Sashisdharan, 2003) and there are now clear policy guidelines and initiatives (DOH, 2005) to redress the inequalities and disparities these communities experience in mental health services. In a consultation exercise to develop a strategy for reducing inequalities in mental health for BME communities (DOH, 2003) a need was identified to develop research methods appropriate for use with BME groups and the need to ensure that all research includes consideration of ethnicity and culture. Particular areas for research and suggestions for appropriate research methods have not been specified.

Services for Children and Young People

The NSF for Children (DOH, 2004b) established clear standards for promoting health and well-being of children. Standard 9 relates particularly to the mental health and psychological well-being of children and young people. In terms of building the evidence base in Child and Adolescent Services (CAMHS). It is suggested that professionals face a particular challenge in that there are significant gaps in the knowledge base for these services. For example, psychological and behavioural interventions have received little research attention, yet they constitute the major work of CAMHS professionals. It recommends that more research is needed to determine effectiveness of such interventions. Innovative approaches should be encouraged and subjected to audit and evaluation. Outcomes should be evaluated from the perspective of service users, including where possible families or key professionals. It is important to note that these recommendations were confirmed by the scoping exercise discussed on page 16.

These policy initiatives have now been in operation for a number of years and it is clear that a range of research priorities were identified to support the implementation of the NSF and guidance related to it. A review of achievements in relation to the NSF was published in 2004 (DOH, 2004). With regard to research and development it reported that 69 projects have been commissioned, which covered primary care, secondary and social care and particular groups of service users such as those from BME groups, prisoners and patients in secure hospitals. The review concluded that despite this progress, there is still a need for high quality research relevant to mental health promotion, primary care, access to services, support to carers, suicide and the need for research on issues relating to particular groups such as BME groups and women.

3.1.2 Clinical Guidance to support the NSF

The National Institute for Clinical Evidence (NICE) is commissioned by the DOH to provide clinical guidance to support the NSF which includes technology appraisals to consider the evidence that a particular treatment or intervention is effective.

Guidelines have been published on Schizophrenia, Eating disorders, Self-harm, Depression, Anxiety, and Depression in children. We searched these guidelines for recommendations for research related to service development or specific interventions that could lead or contribute to patient and care-centred services. We report here on the recommendations from guidelines for Schizophrenia, Depression, and Depression in Young people.

Schizophrenia

The guideline on Schizophrenia emphasises the complexity of the condition and the need for a complete service response including a service user focus. In terms of interventions there were recommendations for research into the following:

- randomised trials to evaluate the use of cognitive behavioural therapy for people at their first episode of schizophrenia,
- a need for more research on the development of effective interventions for managing physical health of people with schizophrenia in general practice,
- randomised control trials are needed to evaluate the use of family interventions for families of people with schizophrenia presenting for the first time,

Depression

The guideline on Depression recommends that for mild to moderate depression appropriate psychological treatments should be offered as treatment options. In relation to research the guideline recommends more generally that research is needed on the identification, treatment and management of depression in primary and secondary care. More specifically, it recommends that adequately powered RCT's are needed to compare the efficacy of different models of behaviour therapy; research on the efficacy of studies on the role of guided self-help in a stepped care programme and trials should be undertaken on the efficacy of the range of social support interventions for socially isolated and vulnerable groups with depression. We believe that research on these interventions could support the evidence base towards developing the service user report's call (referred to on page 16) for promoting a more holistic model of mental health.

Depression in Young People

The guideline on depression in children and young people supports the call for research on the efficacy (including measures of family and social functioning as well as depression) and the cost-effectiveness of individual CBT, systemic family therapy and child psychodynamic psychotherapy

compared with other treatment. It also highlights the need for a qualitative study to examine the experiences in the care pathway of children and young people and their families to inform decisions about the most appropriate pathway of care.

In terms of service development a need for research to the effectiveness of specialist teams (e.g., crisis resolution and home treatment, early intervention teams) as compared to other ways of delivering mental health services to people with schizophrenia.

Together, the policy initiatives and clinical guidelines reviewed above identify a range of areas and priorities for research which are summarised below:

- A more holistic model of mental illness should be researched including how to increase the psychological components of care;
- Outcomes: research should include outcomes that are evaluated from the perspectives of service users and carers;
- Interventions: research is needed to study the efficacy of support interventions for socially isolated and vulnerable groups; research is needed to study the efficacy of behavioural interventions for schizophrenia and depression;
- Acute Care: research is needed to develop and evaluate the effectiveness of service user-led alternatives to acute care; research is needed to evaluate the effectiveness of acute services in the context of the NSFMH;
- Suicide: research is needed for detailed studies of high risk groups from which conclusions can be drawn for prevention; and there is a need for intervention studies with more common outcomes that will act as 'proxy' measures for suicide, e.g., non-fatal deliberate self-harm.
- Research should address the issues and needs of women and BME groups;
- Research is needed into access to services; and
- Research is needed to evaluate the efficacy of health promotion.

3.1.3 Research Priorities from the literature

3.1.4 Patient-centred services

Definitions of patient-centred services

We searched the literature for definitions and models of patient and carer-centred services and found only two papers where this was specifically addressed for mental health. The NICE guideline on Depression, for example, outlines what could be considered to be the dimensions of patient-centred services. These include the following:

- treatment and care should take into account people's individual needs and preferences,
- people should have the opportunity to make informed decisions about their care and treatment,
- good communication between healthcare professionals and patients is important,
- treatment and care should be culturally appropriate and accessible to people who have additional needs and unless the patient chooses to exclude families and carers, and
- they should have the opportunity to be involved in decisions about the patient's care and treatment.

There is a lack of clarity about the meaning of patient-centred care in the literature. Although Government policy has defined it as a priority, there is little clarity about what it means and involves. (DOH, 2000b: NHS Plan). It seemed that in mental health services patient and carer-centred care is often equated or conflated with service user and carer involvement or those activities that can promote involvement such as setting up user and carer groups, encouraging service user participation in decision making structures and contributing to service development and planning.

To overcome this shortcoming in the literature, we searched more generally for descriptions and definitions of patient-centred services. We found that patient-centred care is much more clearly defined in the general health literature and some reference will be made to this. Lewin et al, 2002 (p. 127) define patient-centred care as shared control of the consultation and decisions and considering the participant as a whole rather than focusing on the disease process. Patient-centeredness in general health care is conceptualised within the context of the contact between the patient/service user and the professional (Mead & Bower, 2000). Mead and Bower's (2000) review discusses five conceptual dimensions of patient-centeredness, i.e., bio-psychosocial perspective; 'patient-as-person'; sharing power and responsibility; therapeutic alliance; and 'doctor-as-person'. In terms of service user and carer involvement (discussed below) the focus has been on the first 4 of these dimensions. Mead & Bower (2000) also reviewed the approaches to measuring patient-centeredness and found the most common ones were self-reports and external observation methods.

It has been suggested that perceptions on patient-centred care is crucial in how it is delivered. In a study to survey attitudes and perceptions of health professionals and patients on patient-centred care Gillespie et al (2004) found diversity in the understanding of patient-centred care. Health professionals for example, adopted a medical model of patient-centred care where professional priorities determine patient need, whereas patients described patient-centred care in the context of a social or whole person model of health. For professionals the emphasis was on the need to inform patients and to engender trust in patients. Service users on the other hand described their ideas for involvement in the planning and delivery of services rather than face-to-face encounters. The negotiation of shared definitions therefore becomes important.

The emphasis in the literature seems to be on the organisational end of patient-centeredness in policy terms, rather than what happens to individuals despite the fact that only a small number of service users will be involved in service delivery and planning whereas all service users and their families and carers will come into contact with services at the individual level. The evidence on patient-centred care at the individual level should be reflected in policy developments in order to change the

culture of the service and the attitudes and behaviour of health professionals. Patient-centred care seem to be a managerial concern rather than the concern of mental health professionals: we argue that it should be both.

There is evidence to suggest that some interventions to promote patient-centred care in the clinical consultation may lead to significant increases in the patient-centeredness of the consultation process, that is, identifying and clarifying the patient's beliefs and concerns; communicating about treatment options; and increasing levels of empathy. Training health care providers in patient-centred approaches may impact positively on satisfaction with care.

Lewin et al, (2001: 16) found that no single study used measures explicitly designed to assess the patient-centeredness of the consultation and that there is no gold standard measure for patient centeredness. Gillespie, R, et al (2004) concluded that the effects of the concept of patient-centred care on the relationship between professionals and patients are not known and would require further investigation.

We support the suggestion that there is a need to take account of the full spectrum of potential activities that constitute patient-centred care (Gillespie et al, 2004).

Models of patient and carer-centred services

At the heart of the Government's modernisation agenda to improve mental health services and the quality of care is investment towards the provision of new teams, staff and services. There is now a clear focus on social inclusion and recovery. Given that some of these initiatives are in the early stages of implementation, we do not yet have sufficient evidence to show to what extent they contribute to patient and carer-centred services. We reviewed the available evidence on the impact and effectiveness of some these relatively new services, e. g., early intervention, assertive outreach and crisis resolution. A systematic review by Marshall & Lockwood (2004) to evaluate the effects of early detection and treatment of people with prodromal symptoms, the use of early intervention in the first episode of psychosis, and phase specific treatments for psychosis found that the evidence was inadequate to make conclusive judgements about the effects of early intervention teams. They found that teams delivering specialised care for people with early psychosis are superior to standard care for maintaining contact with professionals and reducing readmissions to hospital. Marshall and Lockwood (2005) suggest that this may be due to increased levels of contact between service users and professionals and the fact that the contact was more personalised.

A review on clinical trials for Assertive Community Outreach found that there is a reduction in readmissions to hospital, but in general there has been no difference in symptoms and behaviour of individuals who received assertive care and those who received standard care. The reasons for this has not been explained fully, but we suggest that this may be due to the fact that these new service types still operate within a narrow illness/disease framework and neglects the factors that may contribute to patient and care-centred care. Lewin, et (2001) also posited that some of the problems may arise because service providers focus on disease management rather than on people, their lives and their health concerns.

Self-help is a new development in mental health care. Rogers et al, (2004) evaluated a self-help clinic in primary care and found that the clinic helped to restore a sense of

coping, but patients were not familiar with the concept of self-help and expected formal types of services, e.g., counselling. This seem to have implications for the expectations and perceptions that service users have of services and work that is needed to inform and educate them about the nature of services that differ from the conventional modes of service provision. The evidence on self-help initiatives is limited, so we need further evaluations of self-help initiatives and the role they play in patient and carer-centred services.

With increasing access to the internet and modern technologies there is anecdotal evidence that the internet can provide a source of support (Sa'adiyah, 2002) for service users, offers a way of meeting new people, a way of finding new information, etc. It can also be a way of disseminating information about mental illness, medication and services for families and carers. We need studies to examine to what extent modern technology can be used to deliver patient and carer-centred care. What is the impact of new technology on the organisations and the organisation of care? For example, we need to explore the impact of the use of mobile phones as prompts or reminders to attend appointments, or take medication. We need to research the impact of computer programmes to assist with diagnosis and management of depression and other mental health problems.

We conclude that much more conceptual work is needed to clarify what is meant by patient and carer-centred services, the dimensions of such services, what constitutes positive outcome measures and the organisational determinants for patient and carer-centred services. We also need a range of methods to evaluate the impact and effectiveness of patient and carer-centred services and the impact of technology on these.

3.1.5 Service user involvement

Service user involvement has been proposed as a means to improving the quality of care in the belief that this will lead to more appropriate and acceptable services (Beresford & Croft, 1993; Simpson & House, 2003).

We found one systematic review to identify the effects of involving service users in the delivery and evaluation of mental health services (Simpson & House, 2002). The review found that service users can be involved as employees, trainers and researches without detrimental effects to them. Where service users have been employed as employees, clients of those services reported greater satisfaction with personal circumstances and less hospitalisation. Involving service users in training also led to more positive attitudes from professionals towards service users. The review concluded that there is little evidence on the effectiveness of programmes to increase service user involvement and recommended more formal evaluations of these programmes.

We found examples of what may be considered to be evidence towards patient-centred services. This included access to advocacy, information about side effects of medication, and greater involvement in decisions about their own care (Noble, et al, 2004; Cleary, et al, 2003). Another study (Meehan, T. et al (2002) to evaluate the impact of a skills development programme for service users found that training programmes for service users can lead to greater involvement.

There seem to be a positive relationship between service user involvement and satisfaction with service. For example, Chamberlain (2005) found that services that promote and support, recovery and inclusion were rated highly; services that are user-controlled were valued and services that combat discrimination were viewed positively. In a study to explore satisfaction with services and quality of life, Blenkiron & Hammill (2003) found that when people are satisfied with other aspects of their lives such as housing, relationships and family life, they are more likely to be satisfied with mental health services. This obviously has implications for the social inclusion agenda that is currently promoted in the Government's agenda for improving mental health care.

The Care Programme Approach (CPA) has been identified as the primary mechanism for involving service users in their own care and it is also viewed as a system for managing and co-ordinating care (NICE, 2002). Peck, et al (2002) found that when service users were involved in drawing up their own care plans this had a positive impact on outcomes. However, Webb, et al (2000) in a survey to evaluate the implementation of CPA found that many service users were not involved in the care planning procedure nor did they have a copy of their care plan. This situation seemed to have improved according to the National Patient Survey (Healthcare Commission, 2004) which found that 69% of patients had a copy of their care plan. Rose (2003) in a survey to assess service users' understanding of CPA found that they were mostly unaware of the way in which care is coordinated and were often not involved in the care planning process.

The nature of the service user's relationship with their key worker and psychiatrist was also found to have a positive effect on service user involvement (Webb, et al, 2000). Evidence showed that improved therapeutic relationships can lead to better outcomes (Priebe & McCabe, 2006). This has implications for the nature of relationships between service users and professionals. Soffe et al (2004) suggest that the powerfulness of professionals means that the therapeutic relationship can become the site for marginalisation and disempowerment which may have adverse effect on service user involvement. Studies to examine attitudes of professionals towards involving service users in service delivery and development found that negative attitudes is a barrier to effective service user involvement (Anthony & Crawford, 2000; Soffe et al, 2004; Summers, 2003). These studies found that professionals view service user involvement as desirable and necessary for quality care, but there is great variability in the way in which service user involvement is promoted and supported.

Perceptions on needs and defining outcomes seem to have an effect on the nature of the relationship between service users and professionals. This is an area where there are often divergent views. Thornicroft & Slade (2002) found that professionals would often rate psychosis and harm to others as need whereas service users more often identified needs for information on treatment, company, welfare benefits, transport and sexual expression. Lelliot, et al (2001) suggest that self-assessment instruments can prove useful in measuring perceptions and experiences of service users.

A key challenge in promoting patient-centred services is to find ways of changing professional attitudes. There have been suggestions that involving service users in the training of professionals can influence their attitudes towards service user involvement. A study by Happel & Roper (2002) to examine the attitudes of students who have been trained by a service user found that they were more positively

inclined towards promoting service user involvement and patient-centred care. Lammers, et al (2003) suggested that mental health professionals, in particular nurses, are key to promoting a service user agenda in mental health services.

A number of papers focused on the factors that contribute to satisfaction with services. There was however no specific relationship or link identified between satisfaction with services and patient and carer-centred services. There is a need to explore the link or relationship between satisfaction with services and the level of patient and carer-centeredness of services. There is also a need to evaluate models that translate service user and carer involvement into practice.

An area where service user involvement seemed to be lacking was acute inpatient care. A study to evaluate the implementation of an advocacy service in a secure ward, for example, found that this was one of the most effective ways to promote service user involvement (Atkinson & MacPherson, 2001). It was however noted that outcomes for advocacy are difficult to define and measure and that more work is needed to define and develop outcomes for advocacy.

Studies of patient views on safety on an acute ward in London (Wood & Pistrang, 2004) suggested that we need larger scale studies to investigate the variables that may impact on the safety of patients and staff and conceptualisations or perceptions of safety.

Crawford, et al (2005), in a systematic review, examined the effects of service user involvement in health care. They found that the most reported effects are new or improved sources of information, changes to how services are organised, for example extending opening hours, simplifying appointment changes. Only a few studies reported changes to organisational cultures i.e., greater openness to user involvement. The review only included qualitative studies as there were no known observational or experimental studies to explore the effects of service user involvement. There is a greater need to study the effects of service user involvement on the quality of care. Crawford et al (2005) conclude that the evidence base for the effects of service user involvement on use of services, the quality of care, satisfaction with care or the health of service users is lacking.

It is clear from the above that we need further research into the effects of service user involvement and the extent to which these initiatives contribute to the building and development of patient-centred services. We also need research into the best ways of training professionals to adopt and incorporate patient and carer-centred perspectives into their approach to working with people with mental health problems, their families and carers. The evidence shows that CPA is an effective route to service user involvement in planning their care, but we need further work to explore the role of CPA in delivering patient and carer-centred services. We need further research to define a set of outcomes for patient and carer-centred services/care that can accommodate the varying perspectives of service users, professionals and carers.

Do we need to make more explicit the priorities for research evaluating the effects or impact of service user involvement?

Building the knowledge base: User-led research

The Department of Health's Strategy for Best Research in Health (2006), states that research that is focused on the needs of patients and the public, should involve service users, their families and the wider public. However, The NSF for Mental

Health (DOH, 1999) subscribes to a traditional framework, i.e., the hierarchy of evidence for building evidence. This has led to calls for adopting and seeking different paradigms for studying mental health services Faulkner & Thomas (2002). Following the lead of Faulkner & Thomas (2002), we propose that user-led research can be one of the ways to promote and develop patient and carer-centred services. There is a small but growing body of literature that illustrates that research which is led by service users or include them, lead to findings and outcomes that are relevant to peoples' needs and more likely to be put into practice (DOH, 2006; Faulkner & Thomas; 2002; Rose, 2003; Wallcraft, 2004). The advantages of involving service users in research have been identified. It has been argued that it examines issues that are relevant and meaningful to service users and can define standards of good practice in mental health care (Rose, 2001). Evidence shows that participation in research will sometimes yield different and competing results (Rose, et al, 2003; Thornicroft, 2005)

In terms of promoting a patient and carer-centred agenda we need to find the best ways of integrating user-led research with evidence-based medicine (Thornicroft & Tansella, 2005). Faulkner & Thomas (2002) proposed that we need to develop and commission partnership research. It has been suggested that independent user-controlled research is needed to study all aspects of psychiatric drug issues (Lehman, 2005; Trivedi & Wykes, 2002). We also need to seek new research methodologies to allow for effective participation of service users and carers in research. More participatory approaches such as action research and observational studies are needed to promote the knowledgebase on patient and carer-centred services (Chamberlain, 2005). It has to be acknowledged that service user-led research, though valuable, cannot singly fulfil the needs for a strong evidence base on patient-centred services. We therefore agree with Thornicroft & Tansella's (2005) suggestion that a 'multi-perspectives' paradigm is needed to integrate various sources of evidence.

3.1.6 Carer-centred Services, carer involvement and support

The needs and interests of families and carers have now received prominence in recent policy developments and legislation. (DOH, 1999, DOH, 2000a). It has also been acknowledged that carers should be involved in service development, planning and delivery. There are numerous suggestions in the literature for ways to achieve carer involvement, but again no indication of the dimensions of carer-centred services. Methods or mechanisms to increase or achieve carer involvement included: access to information, involvement in decision making, supportive staff and good coordination among services (Noble et al, 2004). In a review of the NSF for Mental Health five years on (DOH, 2004), it has been reported that there has been an increase in carer support services, the number of carer support groups and the number of day services with support for carers.

In terms of the evidence on carer involvement it has been reported that carer involvement in planning local services is much less developed than service user involvement (Commission for Health Inspection, 2003). Some of the barriers to carer involvement have been identified which included a lack of information; perceptions by staff that family members play a part in causing mental illness or that they are interfering or over-protective (Rethink, 2003, Keating et al, 2002); and a significant

barrier to involvement was patient confidentiality issues (Arksey, 2002). Huxley & Pinfold (2006) carried out a scoping exercise to review services for carers and have subsequently produced a good practice guide on sharing information between services users, carers and professionals.

There are however still significant gaps in the literature on carers and the best ways to promote carer-centred services. Arksey et al (2002), for example, identified key areas for research, some of which have been addressed, such as good practice on sharing information and confidentiality. However, some areas have still not been taken on board, such as the need for research to focus on specific groups of carers, i.e. young and young adult carers (Newbrunner & Hare, 2002), Black and minority ethnic carers (Keating et al, 2002), carers in same sex relationships, research differentiating between the effectiveness of interventions for spouse and non-spouse carers, male and female carers, urban and rural carers, working and non-working carers, research into the effectiveness of services for carers of people with mental health conditions such as depression, eating disorders, anxiety disorders, substance abuse, and those with dual diagnosis.

Research has been done to consider effective services for carers, for example the scoping review on effective respite services for carers of people with dementia (Arksey, et al, 2004) found that evidence on the effectiveness of respite care and short-term breaks is limited, yet there was qualitative evidence from carers on the benefits of short term breaks. The scoping exercise made a number of recommendations for future research such as the need for research into new services and different forms of respite care, including carer's preferences. Research is also needed into respite services for particular groups, such as carers for younger people with dementia, black and minority ethnic carers and carers of people with Down's syndrome and dementia. In terms of the organisational context it recommends research into service configurations of respite care provision.

In another study to map good practice within mental health for sharing information between mental health professionals and carers (Pinfold et al, 2004) it was reported that practice varies, policy guidance is inconsistent and that professionals are uncertain about what they may share and that carers are often unaware of their rights. This review identified the need for more evidence to explore the specific information needs and difficulties experienced by carers from BME communities and young carers. It also suggested that research is needed on the implementation of strategies to address effective information sharing to understand which solutions work for whom in practice and why.

The needs of long-term carers continue to be neglected and overlooked (Pinfold & Corry 2003) and there is a lack of research on the long term impact of caring for someone with a mental health problem. There is a need for a greater understanding of the ways in which different communities/cultures view the caring role in mental health and how care and support are provided in these communities (Newbrunner & Hare, 2002). There is a lack of research into the needs of carers who support someone with a dual diagnosis. This last point is very interesting and perhaps needs a bit more elaboration. The paper by Haddock et al might be worth citing here as their intervention involved carers to.

Need research to examine the link between providing support for carers, their ability to cope and the quality of life of the person being supported (Newbrunner & Hare,

2002); need research to understand how different communities/cultures view the caring role and how care is provided in these communities.

3.1.7 Marginalised Groups

Mental Health and substance abuse (dual diagnosis)

Dual diagnosis is commonly used to describe a situation where an individual with mental health problems have a substance misuse of alcohol problem as well. There is agreement that dual diagnosis and supporting someone with a mental illness and substance misuse problems remains one of the main challenges for mental health services (DOH, 2002c; DOH, 2004c). Yet little is known about the best and most effective ways of meeting the needs of this group of individuals. There is a distinct lack of research evidence on which to base service development for people with a dual diagnosis (DOH, 2004c). Jeffery, et al (2000) in a consultation exercise to examine and explore the issues for this service user group found that there is lack of epidemiology of the problem and lack of evidence regarding the efficacy of interventions. Service models for dual diagnosis are at an earlier stage of development. For example, there is evidence of the benefits of therapeutic interventions such as cognitive behavioural therapies for people with schizophrenia, but little is known about the effects for people who have a psychotic disorder and misuse substances.

We need epidemiological studies to assess the nature and extent of the problem and evaluation studies to examine the impact of interventions and different service models to meet the needs of people with dual diagnosis. There is a need for clinical trials to identify the most active and important ingredients of successful therapy for people who misuse substances (Haddock et al, 2003).

Mental Health and Learning Disabilities

Department of Health (2001c) guidance on services for people with learning disabilities suggests that they should be fully involved in decisions and services that affect them. Person-centred planning has been promoted as a mechanism for achieving this aim. The needs of people with learning disabilities who also have a mental health problem have been highlighted in a literature review of access to health care services (Alborz, et al, 2003). Alborz et al (2003) found that there were particular problems relating to the accessibility of mental health services. Longo & Scior (2004) suggest that little is known about the experiences of people with a learning disability and a mental health problem. They found that users of generic mental health services felt less supported by staff, found the environment stressful and report negative experiences of control and restraint. Alborz, et al (2003) found that there appeared to be confusion among carers over the respective roles of learning disability and mental health services and recommended that research is needed into the respective roles of mental health and learning disability services to clarify when and under what circumstances people with learning disabilities should use each service.

We need research into the experiences of people with learning disabilities and a mental health problem of mental health services. We need research to examine to

what extent the use of person-centred planning lead to patient and carer-centred services.

Child and Adolescent Mental Health

Policy guidance (DOH, 2004b) is suggesting a culture change in relation to service user involvement of children and young people. In a study to examine the views of teenage clients and their parents, Hart, et al (2005) found that core values contained in person-centred counselling were valued, feedback was important to partnership and liaison working. Attride-Stirling et al (2001) in a review of child and adolescent services found that a psycho-social approach to working with children and families in the community yields better outcomes. Attride-Stirling et al (2001) recommended that further research is needed to evaluate the effectiveness, accessibility and acceptability of community based services for families and children. The mental health needs of children and young people from black and minority ethnic communities have received little attention (Street, et al, 2005) and further work is needed to understand how best to meet the needs of children and young people from these communities. Hagell, (2002) identified another gap in our knowledge and suggested that the mental health needs of young offenders have been neglected. Hagell, 2002 concluded that the state of our knowledge is inadequate to allow us to be sure how to meet the needs of young offenders and highlighted the need to improve the evidence base on practice, clinical effectiveness and outcomes.

Women's mental health

The government is committed to addressing the inequalities and discrimination that women face in mental health services (DOH, 2002). However, we did not find studies or papers to evaluate specialist provision for women with mental health problems. Nor did we find indications as to whether these interventions have led to patient and carer-centred services. Nor is there available evidence on the most effective ways to address the inequalities and discrimination that women face in mental health services.

In mainstreaming gender, the government has identified that we need research evidence for the effectiveness of women-only versus mixed service provision; research is needed to determine the effectiveness of treatment interventions in women and service evaluation and research should include gender as a key variable in analysis and presentation.

Black and minority ethnic (BME) communities and refugees and asylum seekers

NIMHE has commissioned research to study the pathways to mental health care of BME communities as well as a study into suicide in these communities. There are still some gaps in our knowledge and evidence base in terms of the most effective ways to meet the needs of BME communities. For example, there is some evidence that BME mental health organisations are viewed positively by service users and carers (Keating, et al, 2002) but to date there has not been a large scale study to evaluate the contribution of these organisations to addressing the mental health needs of BME communities. We conclude that enough is known about the issues and concerns of

BME communities and we need studies to evaluate how this information is being used to inform service developments and delivery. We suggest that there is a need for a large scale evaluation of the role of Black-led voluntary sector agencies to identify service philosophies, content of services and outcomes.

Refugees and asylum seekers face particular issues in accessing mental health services. Kenney, et al, (2002) found that they drop out of services early and more often receive pharmacological interventions instead of psychological treatment. We need studies to examine psychological need and to determine the most desirable treatment approaches.

From the literature reviewed above the areas for future research can be summarised in the following topics:

- Conceptual work is needed to identify what constitutes patient-centred care. Similar work is needed to identify what constitutes carer-centred care;
- Interventions: research is needed into the effectiveness of interventions to promote and develop patient and carer-centred services;
- Families and carers: research is needed to evaluate the effectiveness of different service configurations of support services for carers; research is needed on strategies to address effective information sharing between professionals and carers; research is needed into the needs of specific groups of carers, e.g., BME groups, young carers, those who care for someone with dual diagnosis and carers in same-sex relationships; research is needed into the ways in which caring is understood and viewed in different communities; research is needed into the needs of long-term carers;
- Dual diagnosis: research is needed evaluate the impact of interventions and different service models on people with dual diagnosis; research is needed to identify the most important ingredients of successful therapy for people with dual diagnosis;
- Learning disabilities: research is needed into the experiences of people with learning disabilities of mental health services;
- Children and young people: research is needed to evaluate the effectiveness of community based services; research is needed into the needs of specific groups of young people, e.g., young offenders and young people from BME communities;
- Gender: the need for research into the effectiveness of interventions that are specifically designed for women;
- BME communities and refugees and asylum seekers: research is needed into issues of access to services; research into ways in which the current evidence on these communities can be used to develop effective services; and large scale evaluations of black-led voluntary services to patient and carer-centred care.

3.1.7.1 Discussion

Patient and carer-centredness is now enshrined in mental health policy and every mental health service ought to subscribe to these ideas. In this literature synthesis we found that this seems to be more of a statement of good intent and could not find any clear definition of what constitutes patient and carer-centred mental health services. We have also found that patient and carer-centredness are often conflated to mean the same thing. From this synthesis we suggest that there should be clear distinctions between the two concepts. In the absence of a clear definition we believe that patient-centredness relates to choice, access to information, participation in

decisions about their care and services that promotes a more holistic model of mental illness including recovery. In terms of carer-centredness we suggest that this is about carers having the right to have their needs assessed independently, access to services that would support them in sustaining the care giver role and where the service users wishes, for the carer to be involved in decisions about the treatment of the person for whom they are providing care.

There exists a sound policy framework to achieve the vision set out in the NSFMH and the NHS Plan, including a research strategy to support the implementation of the modernisation agenda. There is evidence that research has been undertaken to advance this agenda, but the synthesis of policy documents, NICE guidelines and research literature shows that there remains a number of areas that require further research attention. These are:

- Access to services,
- Primary care,
- A more holistic model of mental illness should be researched including how to increase the psychological components of care;
- Defining outcomes from a service user perspective – acknowledging that some work is underway on this topic,
- Defining outcomes from a carer perspective,
- Interventions: research is needed to: study the efficacy of support interventions for socially isolated and vulnerable groups; the efficacy of behavioural interventions for schizophrenia and depression; and research is needed on interventions for suicide;
- Acute Care: research is needed to develop and evaluate the effectiveness of service user-led alternatives to acute care; research is needed to evaluate the effectiveness of acute services in the context of the NSFMH;
- Studying the needs of specific groups of carers, e.g., carers from BME communities, young carers, carers of people with dementia, and carers in same-sex relationships,

- Research is needed to evaluate the efficacy of mental health promotion.
- The needs and issues of some groups such as BME groups and women.

In addition to these topics we have identified the following:

The need for further conceptual work to identify what constitutes patient and carer-centred care, which should lead to further work on identifying and evaluating best models of practice and effective ways of achieving service cultures that centred on the needs and concerns of service users and their carers.

It may seem that we have only confirmed what is known already, but we would like to highlight that these areas have consistently been identified as areas for further research, but it seems that commissioners and funders of research as well as the research community have not taken any of these suggestions seriously. We suggest that this may also be a reflection of the capacity of the research community to undertake research that will enhance our knowledge base in relation to these topics.

The priorities identified through the synthesis will be presented thematically rather than by rank ordering. The priorities are summarised in the following section.

4 Research Priorities

Patient-centred care

Research is needed to identify:

- What patient-centred care means,
- What its key dimensions are,
- Which interventions constitutes patient-centred care,
- Reliable and appropriate tools/outcome measures to assess the effects of interventions to promote patient-centred care, and
- Best ways of training professionals to adopt patient-centred approaches in their practice.

Service user involvement

Research is needed to:

- Evaluate how service user involvement can be translated into patient-centred care,
- Evaluate the role of the care programme approach in delivering patient and carer-centred care, and
- Evaluate to whether participatory approaches, such as action research and observational studies contribute to the knowledge base on patient and carer-centred mental health services.

Carer-centred care, carer involvement and support

Research is needed to:

- What carer-centred care means,
- What its key dimensions are,
- Which interventions constitutes carer-centred care,
- evaluate how carer involvement can be improved and how this can be translated into carer-centred services,
- Study the long term impact of caring,
- Identify the needs of specific groups of carers such as young carers, carers from BME communities, carers in same-sex relationships and those who support someone with a dual diagnosis, and
- Differentiate between the effectiveness of interventions for specific groups of carers, e.g., spouse and non spouse carers, female and male carers, etc.

Marginalised groups

Research is needed to:

- Study the experiences of people with learning disabilities of mental health services,
- Examine to what extent person-centred planning contributes to patient and carer-centred services,
- Study the impact of different service models to meet the needs of people with dual diagnosis,
- Set up clinical trails to identify the most important ingredients of successful therapy for people with dual diagnosis,

- Improve the evidence base on practice, clinical outcomes and effectiveness of services for children and young people,
- Understand how to best meet the needs of particular groups of young people, such young people from BME communities and young offenders,
- Determine the effectiveness of treatment interventions in women,
- Service evaluation and research should include gender as a key variable in analysis and presentation.
- Examine progress in reducing the inequalities and disparities in services for BME communities, and
- Study the extent of psychological need in refugee and asylum seeker communities and to determine the most desirable treatment approaches,

General Priorities

Research is needed to:

- Explore how a more holistic model of mental illness could promote patient and carer-centred services,
- Examine how we can increase the psychological components of care,
- Evaluate the effectiveness of acute services and the efficacy of user-led alternatives to inpatient care
- Evaluate effectiveness of behavioural interventions, e.g., for schizophrenia, and depression,
- Study the efficacy of support interventions for socially isolated and vulnerable groups;
- Explore the most effective ways of improving access to appropriate care, and
- Evaluate the efficacy of mental health promotion

Some of priorities identified above are 'people' focused (i.e. carers, patients and marginalised groups). The remaining priority is about clarification of patient-carer centred concept, but also about identifying what approaches can be taken by staff, carers and patients to achieve this. We believe that to achieve patient and carer centred mental health services requires changes in attitudes of each set of stakeholders, and changes in culture and organisation of services to accommodate a shift towards more patient-carer centred care.

There is still a great deal of work needed to come to a consensus about the meaning of patient and carer-centred mental health services, what their dimensions are how to develop such services and what evidence base we need to build effective patient and carer-centred services. We believe that it is only once a clear conceptual framework for patient and carer-centred services has been developed that we can achieve the transformation of mental health services envisaged in the NSFMMH and the NHS Plan and measure to what extent mental health services have achieved this ideal.

We conclude that some of the difficulties we've experienced in carrying out this synthesis is largely due to the broad scope of the remit, which ultimately means that this makes it difficult to provide an in-depth analysis of the priorities for research. We believe that this literature synthesis were able to identify a range of research priorities that should enable us to increase our knowledge and evidence base on patient and care-centred mental health services.

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Appendices

Appendix A – Search Strategy

We split the search into several parts, according to various groups using mental health services. In each case we started off with a simple subject heading search, before conducting a more specific “free-text” search which covered the various aspects of the topic in hand.

WE searched PsycINFO, Medline, Embase, Cinahl, ASSIA and PubMed. All references were downloaded using the EndNote program.

Key: SH=Subject heading search and FT=Free-text search.

1. Mental health services and patients

SH: Mental health services

SH: Patient

FT: Mental health service or mental health services

FT: Patient(s) or User(s) or Customer(s) or Client(s) or Consumer(s)

2. Mental health services and carers

SH: Mental health services

SH: Carers

FT: Mental health service or mental health services

FT: Carer(s) or supporter(s) or significant other

FT: Family or families

3. Mental health services and ethnic minorities

SH: Mental health services

SH: Ethnic groups

FT: Mental health service or mental health services

FT: Ethnic group(s) or Ethnic minority/minorities or ethnic or ethnicity

4. Mental health services and people in prison

SH: Mental health services

SH: Prisoners

FT: Mental health service or mental health services
FT: Prisoner(s) or inmate(s) or jail or gaol or prison

5. Mental health services and asylum seekers

SH: Mental health services
SH: Asylum seekers
SH: Refugees

FT: Mental health service or mental health services
FT: Asylum or asylum seeker(s) or refugee(s)

6. Mental health services and homeless people

SH: Mental health services
SH: Homeless
SH: Homeless mentally ill

FT: Mental health service or mental health services
FT: Homeless or homeless people or homeless persons
FT: Shelter or shelters

7. Mental health services and learning disabilities

SH: Mental health services
SH Learning disabilities

FT: Mental health service or mental health services
FT: Learning disability/disabilities or intellectual impairment or mental impairment or learning difficulties or mental retardation or mental handicap or mentally handicapped.

8. Mental health services and physical disabilities

SH: Mental health services
SH: Physical disorders
SH: Physical disorders (attitudes towards)

FT: Mental health service or mental health services
FT: Physical disorder(s) or physical handicap or physically handicapped or physically impaired or physical impairment

9. Mental health services and people who are excluded

SH: Mental health services
SH: Eating disorders
SH: Self destructive behavio(u)r or self mutilation or attempted suicide
SH: Anxiety disorders or panic disorders

SH: Personality disorders
SH: Dual diagnosis

FT: Mental health service or mental health services
FT: Eating disorder(s) or anorexia or bulimia or binge eating
FT: Self harm or self harming behaviour/behaviour
FT: Anxiety or anxiety disorder(s) or panic or panic disorder(s) or panic attack(s)
FT: Personality disorder(s) or antisocial personality disorder(s) or borderline personality disorder(s) or narcissistic personality disorder(s) or OCD or obsessive compulsive personality disorder(s)
FT: Dual diagnosis or diagnoses

10. Mental health services and people older than working age

SH: Mental health services
SH: Aging
SH: Gerontology
SH: Retirement

FT: Mental health service or mental health services
FT: Aged or aging
FT: Older people or old people or elderly
FT: Retirement or retiring or retire

11. Mental health services and people younger than working age

SH: Mental health services
SH: Early child development
SH: Infant development

FT: Mental health service or mental health services
FT: Early childhood or young children or toddler(s)

12. People with mental health problems and choice

SH: Mental health disorders
SH: Choice

FT: Mental health problem(s) OR mental health disorder(s)
FT: Choice(s) OR empowerment OR participation or decision making OR options

13. People with learning disabilities and choice

SH: Mental health disorders
SH: Choice

FT: Mental health problem(s) OR mental health disorder(s)
FT: Choice(s) OR empowerment OR participation or decision making OR options

FT: Learning disability or disabilities OR learning disorder(s) OR intellectual impairment or mental impairment or learning difficulties or mental retardation or mental handicap or mentally handicapped.

14. Searches relating to patient and carer-centred services

- Patient-centred/services/mental health services,
- Carer-centred/ services/mental health services,
- Service users/mental health/mental illness,
- Carers/ mental health/mental illness,
- Service user involvement/ mental health, and
- Carer involvement/ mental health

Appendix B – Policy Literature Table

Author & Year	Target Group	Aims	Recommendations for Research	Setting
Department of Health (Jan 2006)	Community Health Services	a) better prevention services with earlier intervention; b) more choice and a louder voice; c) more on tackling inequalities & improving access to community services; & d) more support for people with long-term needs	As our investment in health grows, primary care and community services will grow faster than secondary care. Put people more in control; make services more responsive; focus on those with complex needs; shift care closer to home. People and patients want more safe health & social care in the community; not only better for people's health 'well-being' but also provides better value for public money.	UK
Department of Health (2005)		Choosing health	To increase funding for public health research to support delivery of this White Paper.	UK
Department of Health (Jan 2004)	Children and Young People	Establishes clear standards for promoting health and well-being of children. Standard 9 relates particularly to the mental health and psychological well-being of children and young people. In terms of building the evidence base in Child and Adolescent Services (CAMHS).	More research is needed to determine effectiveness of such interventions. Innovative approaches should be encouraged and subjected to audit and evaluation. Outcomes should be evaluated from the perspective of service users, including where possible families or key professionals.	UK

Department of Health (2003)	BME Communities	A report of a consultation exercise to reduce inequalities and disparities in mental health services for BME communities	Does not make specific recommendations for research, but suggest that issues of ethnicity and culture should be considered in all research and that appropriate methods should be developed for research with these communities	UK
Department of Health (2002)	Carers and families of people with mental illness	Help local MH services develop support services for carers of SU's. Guidance on developing & sustaining MH carer support services	This guidance suggested that there was a lack of clear evidence to support the effectiveness of any specific service configuration for carers of people with mental health problems. A further suggestion was that the impact and success of carer support services should be evaluated and that carers should be fully involved in this process.	UK
Department of Health (2002)	Women's Mental Health: Into the Mainstream	A consultation document to develop a framework for the delivery of comprehensive, high quality, mental health services that meet the needs of individual women.	Gender should be a key study variable if better understanding of the differences in mental ill health of women and men, and the research is need on the effectiveness of different interventions	UK
Chartered Society of Physiotherapy (2002)	Mental Health & Learning Disabilities	Looking at effect of physical activity in Schizophrenia; Tackling inactivity & obesity in children & adults with learning disabilities; Exercise & Depression; Exercise & Heroin withdrawal; Rebound therapy & learning disabilities; Acupuncture & Depression; Massage & Heroin withdrawal; Falls prevention & dementia; Sleep systems/lying support & complex physical disability		UK

Department of Health (2001)	Suicide Prevention	The strategy seeks to reduce the risk in key groups, promote mental well-being in the wider population, to reduce the availability and lethality of suicide measures, improve reporting of suicidal behaviour in the media, and to promote research on suicide and suicide prevention	a) the need for detailed studies of high risk groups from which conclusions can be drawn for prevention, and b) the need for intervention studies with more common outcomes that will act as 'proxy' measures for suicide, e.g., non-fatal deliberate self-harm	UK
Department of Health (2001)	Inpatient services	aims to assist the reorganisation of inpatient services to adequately reflect the value that underpins all mental health policy	recommended an urgent need to commission research and evaluation on acute service effectiveness in the context of the NSF for Mental Health	UK
Mental Health Foundation (2005)	Mental and Public Health	Provides overview of <i>Choosing Health</i> , government's recent public health White Paper. Aims to identify gaps and opportunities in White Paper & provide framework for addressing these.	Key to national health improvement is more people making healthier choices more of the time. People are more likely to take more control over their own health if they have more control over their lives. Emotional well-being underpins good physical health & reduces likelihood that children/young people will take inappropriate risks. A focus on individual stress can be counterproductive - leading to failure to tackle underlying causes of problems in the workplace. Real task is to improve quality of jobs by reducing monotony, increasing job control & applying apt HR practices & policies orgs need to ensure that they adopt approaches that support overall health & well-being of their employees	UK

Rethink (2003)	Carers	Asks how easy is it for carers of people with mental health problems to access support, information and services they need to do vital but unheralded job.	Carers want to be involved, valued and want to secure best care as early as possible for the person they care for. Too often, they are left out of loop by professionals, feel undervalued & left to fall back on family/friends for support. Quality services, easily accessible round-the-clock support & open access to professionals are still at premium. UK
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Appendix C – Research Literature Table

Author & Year	Sample	Research Methods	Aims	Main findings & Research Recommendations	Setting
Anthony <i>et al</i> (2000)	Mental Health Nurses	Semi structured interviews	Perspective of MH nurses on SU involvement in care planning	MH nurses value concept of SU involvement but consider it problematic in certain circumstances	UK
Blenkiron, Hammill (2003)	Patients of CMHT in N.Yorks	Questionnaire	Determine patient satisfaction with mental health care and quality of life	Patient satisfaction ratings been promoted as an outcome measure when evaluating quality of MH services. Age and general quality of life not directly under control of professionals, factors that can influence individual's satisfaction	UK
Cleary <i>et al</i> (2003)	Acute Mental Health units inpatients	Satisfaction-with-services & discharge questionnaire	Consumer feedback on nursing care & discharge planning	Most satisfied with care, staff, treatment and overall stay in hospital. 95% indicated discharge arrangements explained & 90% satisfied with them	Australia
Dale <i>et al</i> (2004)	Older People & their carers	Questionnaire Survey	Whether this group wanted copies of GP letters	Majority of patients wanted letters about their care but in simple format	UK
Gillespie <i>et al</i> (2004)	Professionals, patients & user groups and consumer Orgs	Qualitative interview study	How term 'patient-centred care' is understood and ways in which intermediate level providers actually deliver patient care	Current DOH policy made patient-centred care priority but hasn't clarified exact meaning. Developing shared understanding of patient-centred care, encompassing all components - important role for new Commission for Patient & Public Involvement	UK

Haddock <i>et al</i> (2003)	Schizophrenic Patients & their carers	assessed on multiple outcomes	Investigate symptoms, substance abuse, functioning and health economy outcomes after CBT programme	Significant improvements in patient functioning compared with routine care over 18 months. NO significant differences between treatment groups found in carer or cost outcomes	UK
Hancock <i>et al</i> (2003)	Older SU's, Carers & Staff	Interviews, Camberwell Assessment of Need for the Elderly (CANE)	Measure and compare ratings of need for older people with MH problems - themselves, carers and apt staff member	Users identified significantly fewer needs than either staff or carers, Also fewer psychological or social needs, daytime activities, company or carer distress than staff or carers.	UK
Hart <i>et al</i> (2005)	27 teenage CAMHS Users & their parents	Focus groups, home interviews	Best practice emphasises user involvement	Process of eliciting views was therapeutic, led to formation of parent-led self-help group.	UK
Jeffrey <i>et al</i> (2000)	Experts in the UK	National 3 Stage Delphi Survey	Evidence for efficacy of treatment programmes for substance misuse & severe mental illness	Best ways to identify people with severe mental illness & substance misuse problems; interventions and techniques considered important	UK
Kennedy <i>et al</i> (2002)	Asylum Seekers	Files assessed by Psychiatrists over 2 year period	Assess social & educational status, trauma experienced, diagnosis & treatment	Overall subjects well educated but socially isolated with poor language skills. Almost 1/3 met criteria for PTSD, Greater than 1/3 met criteria for major depression. Most had no prior psychiatric diagnosis & dropped treatment at early stage	Ireland
Lammers <i>et al</i> (2003)	Mental Health Service Users	Interviews	Looking at the consumer perspective of consumer participation in MH services	Clear need to develop mechanisms to support consumer involvement & influence attitudes of health professions - more valuing of consumer perspective. Nurses in ideal position to lead process. Suggest that research is needed into mechanisms for increasing consumer participation	Australia

Lelliott <i>et al</i> (2001)	Service Users		Carers' & Users' Expectations of Services - Users version (CUES-U) A new instrument to measure the experience of users of MH services	Development & testing of CUES-U suggest it might be feasible to apply self-rated measure of expectations & experiences of Users of MH services. Need further work on testing the use of CUES-U with minority ethnic groups	UK
Lomas <i>et al</i> (2003)	Cardiovascular Patients		Judging relative worth of different health service investments		USA & UK
Longo & Scior (2004)	Service users and carers	interviews	In-Patient psychiatric care for individuals with intellectual disabilities; service users' & carers' perspectives	Accounts of both groups re generic psychiatric settings predominantly negative. Specialised settings frequently described as pleasant environment, supportive, caring staff, good info sharing and satisfactory discharge arrangements	UK
Meehan <i>et al</i> (2001)	Former consumers of mental health services	16 week training programme. Self-evaluation questionnaires & focus group interviews	Assess impact of program on psychological well-being of participants	Exposure to people with acute mental health problems (i.e. inpatients) did not adversely impact on psychological well-being of participants	Australia
Oluwatayo, Gater (2004)	African-Caribbean patients	Case note review	Role of engagement with services in compulsory admission of African - Caribbean patients	Poor engagement with primary care & secondary mental health services of AC patients contributing to high rates of compulsory admission. Aspect of ethnic factors & compulsory admission requires further study	UK
Peck, et al (2002)	Services users, senior managers, carers and staff members	Evaluation study	Evaluate the creation of a joint commissioning board and a combined mental health and social care NHS Trust to assess the nature and development of	User consultation around management and planning increased and service users valued involvement in developing their care plans	UK

service user involvement					
Rogers <i>et al</i> (2004)	Patients and Clinic Users	Qualitative Study, in-depth interviews	Patients' understandings of use of UK primary care-based self-help clinic	Without prior familiarity with self-help, engaging patient as mechanism of change may be difficult. Some expected formal counseling, as per previous experience of services & discussions with GP at point of referral. Takes time & active engagement with self-help materials before patients become aware they're a crucial mechanism of change	UK
Rose (2003)	Mental Health Service Users	Social survey	Investigate whether increasing co-ordination of care at structural level - greater SU involvement	SU s mostly unaware of major way care is co-coordinated but even less involved in it. Recommends that ethnographic research should be undertaken to observe CPA meetings	UK
Secker & Harding (2002)	Service Users	Semi-structures interviews	African & African Caribbean Users' perceptions of inpatient services	On basis of overview, 24 clients, it appeared that all clients had fairly long period of contact with MH, usually including multiple hospital admissions. Average length of contact - 5 yrs. Majority (16) diagnosed as schizophrenic	UK
Soffe <i>et al</i> (2004)	Clinical Psychologists	Postal questionnaire	Clinical Psychologists' views regarding SU involvement in MH services	Indicated that majority of clinical psychologists who replied were supportive of SU involvement	UK and New Zealand
Webb <i>et al</i> (2000)	CPA patients	Survey, 'Your Treatment and Care' assessment tool	Evaluate implementation of CPA from Patient's experience	Many patients don't have copy of their care plan and not involved in care planning procedure. The relationship between patients and psychiatrists need further invvestigation	UK

Wooff et al(2003)	Carers	64 Carers interviewed, measuring experiences of care - giving, stress & SU levels of impairment	Exploration of user's mental health problems, services received and impact of caring on carers	Carers sometimes better judges than care co-coordinators of user impairment. When carers aware of care plans, less negative about caring. Lack of information for carers. Need further investigation into interventions to reduce carer burden	UK
Wood & Pistrang, (2004)	Acute Mental Health ward service users	Interviews, Thematic analysis	Provide a detailed description of experience of being inpatient of Acute Mental Health Ward. Specifically feelings of safety & threat	Patients' accounts characterised by overwhelming sense of vulnerability and helplessness. Staff accounts largely consistent with patients' accounts	UK

Appendix D – Review Literature Table

Author & Year	Population	Review type	Aims	Main findings & Research Recommendations	Setting
Cohen, Eastman (2000)	Mentally disordered offenders (MDOs)	Literature Search	To propose framework for addressing measurement of outcome in relation to MDOs	Current measurement of outcome in relation to MDOs is inadequate. Comprehensive framework that acknowledges multi-dimensional nature of outcome is essential. Researchers must be able to justify the dimensions they prioritise	UK
Lewin <i>et al</i> (2006)	Healthcare providers	2 reviewers independently extracted data and assessed study quality for each study	To assess the effects of interventions for health care providers that aim to promote patient-centred approaches in clinical consultations	17 studies met inclusion criteria. 12 of the 14 studies that assessed consultation processes showed improvements in some outcomes. Also evidence that training health care providers in patient-centred approaches may impact positively on patient satisfaction with care. Further research is needed on interventions to promote patient-centred care.	UK
Marshall & Lockwood	patients	Systematic review	This review aims to evaluate the effects of: i. early detection and treatment of people with prodromal symptoms; ii. the use of early intervention teams for people in their first episode of psychosis; and iii. phase-specific treatments for people in their first episode of psychosis.	Found insufficient trails to make conclusive evidence, but early intervention reduces hospital admissions and maintain longer contact with patients	UK

McCabe, Priebe (2004)	People with severe mental illness	Literature Search	To review methods and findings from studies of therapeutic relationship (TR) in treatment of severe mental illness	The therapeutic relationship is reliable predictor of patient outcome in mainstream psychiatric care.	UK
NHS Centre for Reviews & Dissemination (2000)	Schizophrenia	Systematic reviews	Evidence on the effectiveness of psychosocial interventions used in management of schizophrenia.	Comprehensive care involves not only drugs but provision of ongoing support, valid info, where apt therapies/rehabilitative strategies. Individual psycho-educational interventions can decrease risk of relapse though mechanism to such unclear. Family intervention also decreases risk of relapse, though most marked in early studies by pioneers of technique. Evidence suggests CBT may decrease relapse/readmission rates & also improve patients' mental health. Assertive community treatment (ACT) reduces hospital admissions/time spent inside by 50% - could prove particularly useful where psychiatric in-patient care at premium. Care Programme Approach may help health & social services keep contact with people. The whole area of non-pharmacological treatments is under researched. Well designed, generally randomised controlled trials needed.	UK
Noble & Douglas (2004)	Patients and relatives	Literature Search	What users and relatives want from mental health services	Much attention has been put into working ways to have patients involved in service development & planning, but it's unclear if patients wish to be or feel involved in this. Further work in area would benefit from greater consistency in terminology, measurement & should consider views of other stakeholders, i.e. those responsible for development & resourcing of services	UK

Noble <i>et al</i> (2001)	Patients	Literature reviews pre 1980 & post 1980	The expectations patients held about services, relationship between expectations & outcome of care and impact of interventions to prepare patients for what to expect	Interventions to prepare patients for what to expect found to have beneficial effects on attendance, satisfaction & accuracy of expectations about process of psychiatric care. Future research to focus on developing valid/reliable measures for use in different settings & determining mechanism by which expectations relate to outcomes, clinical outcomes, attendance & satisfaction	UK
Priebe, McCabe (2006)	Clinicians and patients	Literature and own search	To discuss current climate of research on therapeutic relationship (TR) in mainstream psychiatric settings To identify evidence from comparative studies on the effects of involving service users in the delivery and evaluation of mental health services	Specific conceptual & methodological work required to develop better understanding of TRs in psychiatric settings. Further research should include intervention studies; might support stronger emphasis on TRs in training & supervision User can be involved in the delivery of services and this may lead to satisfaction of those who use those services, but more evidence is needed on the effectiveness of programmes to involve service users in delivery and evaluation of mental health services	UK
Simpson, E.L & House, A. O. (2002)	Service users	Systematic review			

Appendix E – Report Literature Table

Author & Year	Target Group	Aims	Conclusions
DOH (2002)	Strategic reviews of research & development	Information for review sought from every NHS organisation that received NHS R&D support funding in financial year 2000/2001. Overview of international MH research through bibliometrics was commissioned to complement findings of this review	The lack of systematic reviews in MH. The areas that were neglected by researchers in relation to the National Service Framework (MH) standards including substantive & focused work on health promotion, research on access to care & research on services to support carers.
DOH (2003)	Children & Adolescents with Learning disabilities	Demands efforts to ensure that services are inclusive & co-ordinated; also demands that services meet defined needs with clear effective/evidence based approaches.	Coordinated provision for child/adolescent MH services through partnership - Mainstream CAMHS & learning disability CAMHS desirable (ensure equality of access & treatment no matter ability); Adolescent & adult services provision to overlap, CAMHS extending at least to 18th, if not 19th birthday for seamless management when adults. Expertise for all those working with children/adolescents who have learning disabilities.
DOH, (2004)	National Service Framework for MH	Review of MH R&D has been carried out to assess research activity in NHS, identify overlaps/gaps, consider need for further development in infrastructure & look towards long-term strategy	Although there are more than 30 externally funded research units, centres & programmes, there were relatively few large-scale, multi-centred projects in progress; few randomised controlled trials; small projects & no external funding; lack of systematic reviews of research evidence; lack of expertise in many NHS orgs carrying out MH research; little research carried out within social services depts; lack of funding sources for MH research; significant gaps in research relating to NSF standards i.e. MH promotion, access to care & types of services needed to support carers; need to ensure involvement of MH service user & carers at all stages of research process.

Institute of Psychiatry, King's College London & Rethink (2006)	Carers & service providers	Identify good practice within MH services for the sharing of information between MH professionals & carers.	Providing carers with information to support them in role can improve outcomes for both service users & carers. Need to be 'cultural shift' within MH system to recognise importance/value of carer's role before they can be meaningfully involved in MH care teams. Carers fear being denied access to important information to help them in their role. Also concerned that their own confidence may be broken. For professionals, one of biggest difficulties is how to identify appropriate carer in order to share or acquire relevant info. Highly complex issues dictate how, when & why info can be shared in MH. NO single 'blueprint' for good practice of info sharing in MH. Service users, carers & professionals to all be involved in generating effective info-sharing strategies. Professionals need training to help understand roles of carers & work with them effectively. Training to be accredited to encourage attendance. Fear about breaching patient confidentiality has frequently created barrier to effective involvement of carers in MH.
Mental Health Research Network (2005)	Older adults	What do we think are the current priorities in research on the mental health of older adults? What are the characteristics of a network which would enable us to carry out the type of research we have identified as priorities?	Two key priorities for research were identified: research is needed to develop and test psychological interventions for people with dementia and their carers; and research to study the effects of interventions for dementia on carers.
NCCSDO, Consultation Report (2002)	Carers	Advise on further research in area of services to support carers (including young carers) of working-age adults & older people with MH problems. Drew on evidence from published & grey literature (both UK and International) about such services. On consultation with key stakeholders - to identify main gaps in existing knowledge & define what's meant by 'effectiveness' & 'cost-effectiveness' in relation to these services	Common understanding of broad pattern of services needed to support carers emerged from discussions with contributors. Highlighted need for range of services which could provide info, support, advice, training and education & time off for caring. Also emphasised central importance to carers of effective services to support person with MH. Consultation highlighted services would only be effective if underpinned by certain underlying principles or demonstrated certain key characteristics. Contributors identified & commented on different ways services were attempting to address support needs of carers. Contributors viewed effectiveness in 5 main ways, in terms of benefit for: Carer; SU; family as unit; service usage; society as a whole. Held mixed views about methods to evaluate effectiveness, e.g. measuring utilisation rates; use of satisfaction surveys/evaluation forms & performance indicators. Also suggested carers should evaluate effectiveness of their own support packages through CPA.

NCCSDO Literature review report (2002)	Carers	Provide a scoping review of evaluation studies of interventions & services to support cares of people with MH problems; to discuss issues relating to effectiveness & cost-effectiveness of interventions; provide insights into areas where there are gaps in knowledge.	Majority of studies carried out in USA (55%). 22% of reports derived from UK. Canada & Australia each accounted for 7%. Studies from rest of Europe and rest of World accounted for remainder. Majority of interventions aimed at carers of people with Alzheimer's (AD) or another dementia (70%). Rest split evenly between carers of people with Schizophrenia (15%) & carers of people with other serious mental illness (15%). Most of the studies focusing on carers of people with AD or dementia were carried out in USA (44%). No study focusing on acute or chronic depression, eating disorders, anxiety or substance abuse was identified. Majority of studies described interventions aimed at family.
NCCSDO, Overview Report (2002)	Carers	Overall aim of study - to advise SDO programmes what further research should be commissioned in area of services to support carers, including young carers, of working-age adults & older people with MH problems.	Participants in consultation shared view that there's no one 'ideal' blueprint or service model. Belief that if services were to be effective, should be tailored to local needs & circumstances. Support for carers was likely to be most effective when offered as part of holistic response to family situation. MH professionals should have positive approach to carers, involve them in decision making & recognise them as 'partners' or 'co-experts'. Services should be person-centred, reflecting diversity of carers. Services should be available at all times, including outside 'office hours' & able to offer rapid response. Service should be 'joined up'; carers' services should be embedded with mainstream MH services. Effectiveness seen in terms of benefits for carers; person supported; family as a whole; impacts on service usage & long-term outcomes for society. Cost-effectiveness - felt is was important to incorporate quality issues relating to support provided rather than simply use quantitative measures such as cost per carer or per hour.

NCCSDO Literature review report (2004)	Carers	A scoping review on effective respite services for carers of people with dementia that found that evidence on the effectiveness of respite care and short-term breaks is limited, yet there was qualitative evidence from carers on the benefits of short term breaks.	recommendations for future research: the need for research into new services and different forms of respite care, including carer's preferences. Need for research into respite services for particular groups, such as carers for younger people with dementia, black and minority ethnic carers and carers of people with Down's syndrome and dementia. In terms of the organisational context it recommends research into service configurations of respite care provision.
NCCSDO Literature review report (2004)	Carers	A study to map good practice within mental health for sharing information between mental health professionals and carers. It reported that practice varies, policy guidance is inconsistent and that professionals are uncertain about what they may share and that carers are often unaware of their rights.	This review identified the need for more evidence to explore the specific information needs and difficulties experienced by carers from BME communities and young carers. It also suggested that research is needed on the implementation of strategies to address effective information sharing to understand which solutions work for whom in practice and why.
NIMHE	Social research in Mental Health	Part of larger programme of work on development of research groups	Results of these exercises were used as the basis for a consultation exercise to refine the priority lists

			Antenatal & postnatal care: how to increase psychological components of care; identification of predictive, modifiable risk factors for mental ill health in the offspring. How best to engage with the wider population; cultural competencies for health promotion initiatives & services; differences in health seeking behaviours of different subsets of the population (by ethnicity, gender, age). Developing evidence base about population based approaches to health promotion & intervention, particularly parenting & school based. How to overcome barriers to multi-agency collaborative working e.g. in assessment, planning, intervention & training.
NIMHE (2005)	Children & Adolescents	Discussing research priorities for child & adolescent MH services.	
NIMHE West Midlands (2002-2004)	BME communities	Elicit extent (if any) of any hidden older people with dementia within the communities; Document levels of understanding of dementia held by community reps and carers; Examine experiences of carers of primary & specialist health services as well as social services in Wolverhampton; Identify areas for service and community development	There was clear need for community capacity building involving recruitment & development of leaders & other BME staff to help provide culturally relevant services; the development & use of BME organisations for service provision; development of representation & advocacy services to support community voice & involvement in decision-making processes.
Rethink	Carers and Families	Coordinate/facilitate delivery of large-scale research projects that'll inform policy & practice as it develops. Broaden scope/capacity of research in MH, including full involvement of service users & carers as well as frontline staff. Help identify MH research needs. Develop research capacity through range of initiatives at local, regional & National level	More carer involvement in setting research priorities required - strategic planning. Where studies involve 'carer perspective', carers should be involved at all stages of research process - developing protocol, identifying core research questions & disseminating finding. Adapting ways of working to allow carers & service users to take part - changing timings of meetings, extending project time-line to include recruitment & training for carers, avoidance of research jargon & translating terminology. More research skills workshops for service users & carers. Establish national carers' research network for people researching carer issues & carer researchers.
Royal College of Psychiatrists		Describes philosophy underpinning modern approach to rehabilitation & recovery. Defines SY population & gives description of range of service provision	New ways of working with service users & carers lies at heart of the specialty. Perspectives of service users & their families, together with care partners, can provide powerful force for development & should be starting point for new work. Need to improve evidence base for rehabilitation.

Sainsbury Centre for Mental Health (2002)	BME persons with MH problems	Aimed at all those who are responsible for planning, provision & delivery of services to this client group, including central Government, NHS, social services, nursing & professional bodies, primary care, Black voluntary sector & other partner organisations. Also aimed at service users and carers	There are circles of fear that stop Black people from engaging with services. Mainstream services are experienced as inhumane, unhelpful & inappropriate. Care pathways of Black people are problematic & influence the nature/outcome of treatment & willingness of these communities to engage with mainstream services. Primary care involvement is limited & community-based crisis care is lacking. Acute care perceived negatively & doesn't aid recovery. Divergence in professional & lay discourse on mental illness/distress. Service user, family & carer involvement is lacking. Conflict between professionals & service users is not always addressed in most beneficial way. Black-led community initiatives aren't valued. Stigma & social inclusion are important dimensions in the lives of service users.
Young Minds (2005)	Young People BME groups	Give a voice to young people between 12-25, from BME backgrounds, regarding their awareness/ experience of & wishes for MH services. Review activity across Tier 1 CAMHS that promotes access for such young people. Identify/analyse barriers to effective access to apt services. Identify examples of promising/innovative practice in this area	Lack of awareness/understanding & poor perception of services promoting MH, amongst many young people from BMT groups & parents, must be addressed. New sources of information about CAMHS needed - through non-traditional routes such as internet, media/radio, social & local faith groups. Information should be available in various languages. To be accompanied by education & training at PCT level to improve early recognition of MH difficulties & apt referral to CAMHS. Provision of training to address CAMHS staff limitations in cultural and religious issues. Important role of voluntary sector needs to be recognised & developed. CAMH services to explore options for developing more flexible/proactive approaches to their delivery.

