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Abstract

The aim of this integrative literature review is to identify mental health service users' experiences of services. The rationale for this review is based on the growing emphasis and requirements for health services to deliver care and support which recognises the preferences of individuals. Contemporary models of mental health care strive to promote inclusion and empowerment. This review seeks to add to our current understanding of how service users experience care and support in order to determine to what extent the principles of contemporary models of mental health care are embedded in practice.

A robust search of Web of Science, the Cochrane Database, Science Direct, EBSCO host (Academic Search Complete, MEDLINE, CINAHL Plus Full-Text), Psychinfo, Psycharticles, Social Sciences Full Text and the United Kingdom and Ireland Reference Centre for data published between 1/1/2008-31/12/2012 was completed. The initial search retrieved 272,609 articles. The authors used a staged approach and the application of pre-determined inclusion/exclusion criteria, thus the numbers of articles for inclusion were reduced to 34. Data extraction, quality assessment and thematic analysis were completed for the included studies. Satisfaction with the mental health service was moderately good. However, accessing services could be difficult because of a lack of knowledge and the stigma surrounding mental health. Large surveys document moderate satisfaction ratings however, feelings of fear regarding how services function and the lack of treatment choice remain. The main finding from this review is whilst people may express satisfaction with mental health services; there are still issues around three main themes: acknowledging a mental health problem and seeking help; building relationship through participation and care; and working towards continuity of care. Elements of the recovery model appear to be lacking in relation to user involvement, empowerment and decision making. There is a need for a fundamental shift in the context of the provider-service user relationship to fully facilitate service users' engagement in their care.

Search terms: Communication, Experience, Mental health, Mental Health Service-User, and Relationships, Service-Providers.

Accessible summary:

- A number of studies have highlighted issues around the relationship between service users and providers. The recovery model is predominant in mental health as is the recognition of the importance of person centred practice.

- The authors completed an in-depth search of the literature to answer the question: What are service-users experiences of the mental health service?
- Three key themes emerged: acknowledging a mental health problem and seeking help; building relationships through participation in care; and working towards continuity of care.
- The review adds to the current body of knowledge by providing greater detail into the importance of relationships between service-users and providers and how these may impact on the delivery of care in the mental health service. The overarching theme which emerged was the importance of the relationship between the service-user and provider as a basis for interaction and support.
- This review has specific implications for mental health nursing. Despite the recognition made in policy documents for change, issues with stigma, poor attitudes and communication persist. There is a need for a fundamental shift in the provider-service user relationship to facilitate true service user engagement in their care.

Introduction

A predominant focus in mental health policy and practice over the last 20 years has been greater efforts to involve people in their care planning. Historically, service-users' involvement in their mental health services was limited (Dunne 2006, Campbell 2005). Understanding the views of the service users remains essential in contemporary mental health in order to identify the extent to which a service is achieving its aims and purpose. The aim of this integrative review is to establish what evidence exists as to the experiences service users' have of mental health services.

Legislations protecting service-users' rights has been introduced and implemented in the United Kingdom (UK) and Ireland (Mental Health Act 2007, House of Parliament and Mental Health Act 2001 Houses of the Oireachtas). Furthermore, new models or approaches to care have been advocated including the recovery model which has been promoted internationally (e.g. New Zealand's Mental Health Commission (MHC) (2011), the Irish MHC (2008) and UK Department of Health (2001). The main elements of the recovery model are greater service-user involvement, modernising the mental health workforce, viewing the person beyond the illness, increased personalisation, facilitating choice of treatments and changes to education programmes. The recovery model seeks to invert the role of the service-user from being a follower to one where they are able to lead change and direct their own care (Sainsbury Centre for Mental Health 2009). The prominence and importance of patient centred care, also identified by Epstein and Street (2011), aims to ensure service users' needs and preferences are respected. A key aim of patient-centred care is to help service-users' make and contribute to, informed decisions about their care.

Research in the early 2000's identified several issues around the relationship between service users and providers. For example Dunne (2006) highlighted that service users continued to experience poor communication and lack of continuity of care. A preliminary literature search did not identify a recent review which addressed experiences across mental health services. Therefore, as the debate regarding the autonomy and rights of service users in mental health continues, it is timely to identify what is known about mental health service users experiences of mental health services.

The aim and methods of the review

The aim of this integrative literature review was to identify how service-users experience mental health services. Mental health service-users are not a homogeneous group with similar experiences, so the focus of this integrative review was the experiences of adults (18-65 years old) who accessed and used a mental health service. Reports relating to specialist services such as homeless services, the utilisation of mental health laws, detention or involuntary admission, clinical treatments or reports which outline changes in work practices in specific areas were excluded as outlined fully in Table 1. The focus of this review was on database searches to in order to extract evidence from systematic reviews and primary empirical qualitative and quantitative studies (Table 1).

An integrative review was undertaken to address the aim of the review. This approach is increasingly recognized as appropriate to inform evidence based practice. The integrative review synthesize findings from a diverse range of primary experimental and non-experimental research methods in order to provide a breadth of perspectives and a more comprehensive understanding of a healthcare issue(Whittemore and Knafl 2005). Given the aim was to evaluate services users' experiences, an integrative review was considered to be the appropriate method. The approach reported here reflects key aspects of the systematic review methods advocated by the Cochrane Collaboration and Scottish Intercollegiate Guideline Network (SIGN 2008) and takes cognizance of PRISMA standards for reporting systematic reviews (Moher et al. 2009).

The search terms in this review were organised under two search strategies. Firstly, the search terms centred on the Multidisciplinary Team (MDT) as they are the main mechanism for the delivery of mental health care. However, little data was found regarding service-users' experience of MDTs or community mental health teams (CMHT). Consequently, the search terms were broadened to focus on the experience of service-users. This resulted in a significant number of papers for inclusion (see Figure 1). These were reduced through using exclusion/inclusion criteria (see Table 1) and the use of electronic limiters within each database and manually. The use of electronic limiters was not uniform throughout the databases due to differences in how databases structure their limiters. The limiters were mainly used to restrict the years of results (2008-2012), country of origin, to include data from peer reviewed journals and exclude data which did not discuss issues in the field of mental health. The timescale of the searches, 1/1/2008 to 31/12/2012, were judged to be relevant to assess contemporary mental health care and the impact of mental health policy. The electronic limiters reduced the number of articles to 5,671. These articles were then reviewed by reading their abstracts to determine their relevance. Following this process**,** 202 articles were printed out for deeper inspection.

After the removal of duplicates and articles which did not meet the inclusion criteria, 34 articles were included in this review (Figure 1).

Data synthesis

Data was extracted using a predetermined format. The key information extracted included the aims, objectives, methodology and key findings of the 34 included articles. A thematic analysis of the data was completed. The trustworthiness of the analysis was enhanced by review and dialogue around the emerging analysis and interpretation with the co-authors and supervisors of this review. The database which produced the most articles was Web of Science and the most successful search term was 'Mental health service-users and relationships*'.

Quality assurances procedures

The 34 articles were quality appraised using the Critical Appraisal Skills Programmes Checklists (Accessed 18/09/2013). Articles were not excluded on the basis of their quality assessment but rather that the purpose was to allow overall conclusions to be drawn as to the strength of evidence which exists. The quality of research was moderately good and originated from a variety of sources. Overall**,** the review found twelve quantitative studies, thirteen qualitative studies, six mixed methods and three reviews of the literature. The origin of the studies broke down as follows: twenty-one from the UK, eight from Ireland, two from Norway, two from Australia and one from United States of America (USA).

The findings are presented in three themes which illuminate the experience of service-users: acknowledging a mental health problem and seeking help; building relationships through participation in care; and working towards continuity of care.

Table 1: Databases, search terms, inclusion/exclusion criteria of the literature review

Databases searched (1/1/2008 – 12/12/2012)

- Web of Science
- Cochrane Database
- Science Direct
- EBSCO host (Academic Search Complete, MEDLINE, CINAHL Plus Full-text, Psychinfo, Psycharticles, Social Science Full Text and UK and Ireland Reference Centre).
- Websites of the National Service-User Executive, Mental Health Commission Ireland, The Care Quality Commission and NHS surveys
- Hand searching of key reference lists.

Key search terms

1 (Multidisciplinary Teams and), 2 (Mental Health Service-users), 1 and Mental health*, 1 and psychiatry*,1 and Psychiatric Nursing*, 1 and Mental Health Nursing*, 1 and Occupational Therapists*, 1 and Psychiatrists*, 1 and Psychologists*, 1 and Social Workers*, 1 and G.P.s*, 1 and Processes and Workings,1 and Psychiatric Service-users*, 1 and Mental Health Service-user*s, 1 and Psychiatric Clients*, 1 and Mental Health Clients*, 1 and Psychiatric Patients*, 1 and 2 and satisfaction*, 1 and Mental Health Patients and satisfaction*, 1 and satisfaction*, 2 and satisfaction*, 2 and impact*, 2 and experiences*, 2 and relationship* and Team working in healthcare

Inclusion criteria

- Papers from peer reviewed journals published from 1/1/2008 to 31/12/2012.
- Original quantitative, qualitative research, Integrative literature and systematic reviews
- Articles written in English.
- Articles from Europe, North America and Australia/New Zealand due to their comparable mental health systems.

Exclusion criteria

- Research from child/school services or specialist services such as military, forensic, care of the elderly, crisis intervention teams, rehabilitation or homeless services as the main focus of the questions posed in this literature review relates to generic adult mental health services.

- Research which explores the use of detention, use of mental health laws to administer treatments against a person’s will or involuntary orders.
- Research which explores the experiences of persons over the age of 65 and under 18.
- Articles which explored employment strategies, models of care, reports which outlined changes in work practices in a specific service or treatments/interventions used in mental health care.
- Articles that explored the physical health of mental health service-users.

Figure 1 Search results

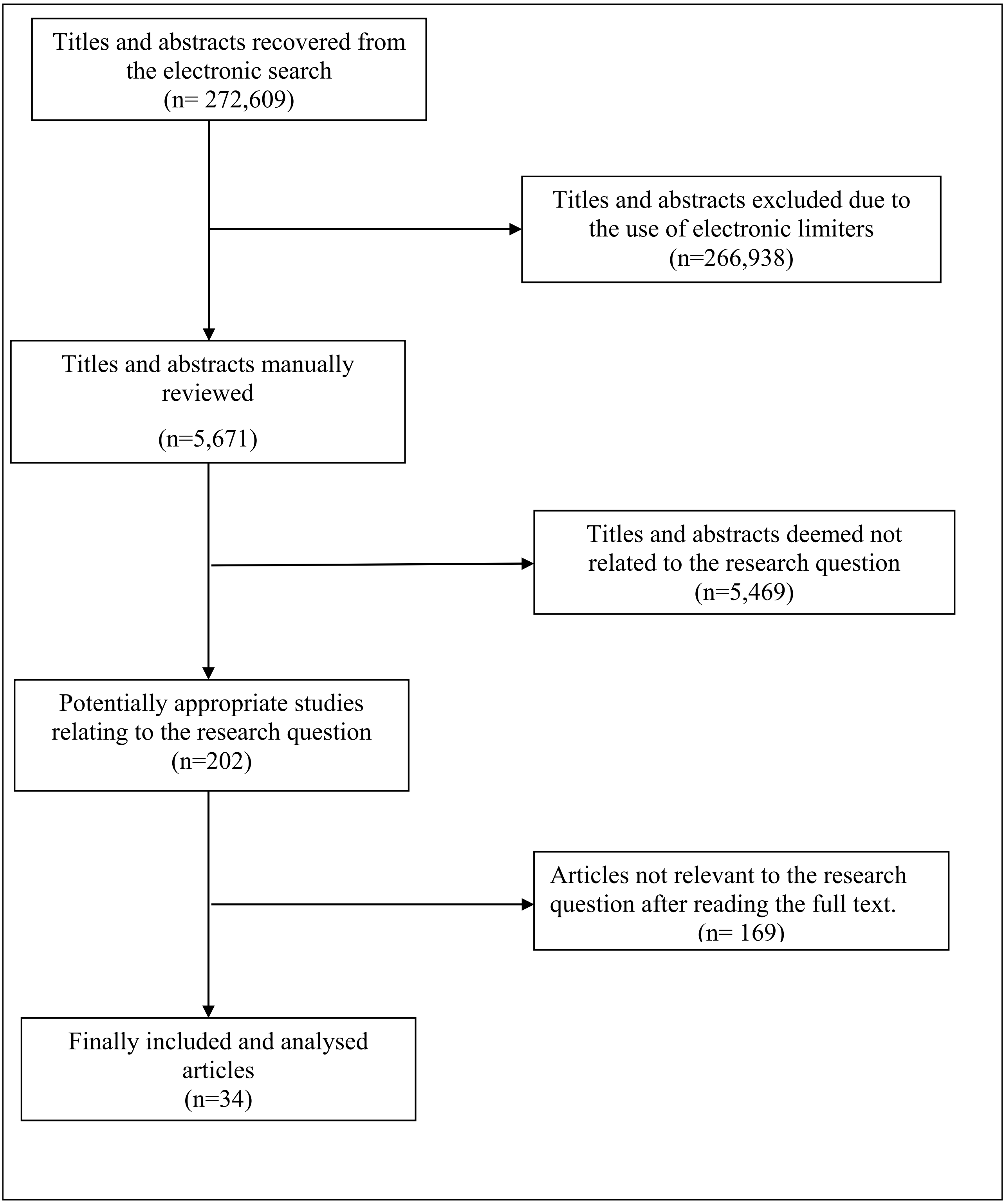
Titles and abstracts recovered from the electronic search (n= 272,609)
Titles and abstracts excluded due to the use of electronic limiters (n=266,938)
Titles and abstracts manually reviewed (n=5,671)
Titles and abstracts deemed not related to the research question (n=5,469)
Potentially appropriate studies relating to the research question (n=202)
Articles not relevant to the research question after reading the full text. (n= 169)
Finally included and analysed articles (n=34)

Table 2: List of articles included in the review

Study	Participants	Interventions	Results	Quality Assessment
Arbuckle et al. (2012) UK	Mental health service users who utilise CMHTs.	Quantitative, Survey, n=24	Need to involve service-users in the decision making process. The relationship between the service-user and the keyworker is central to service-users attachment to their CMHT	Moderate: Small Sample. Unambiguous methods and results sections
Burns et al. (2009) UK	Mental health service users who utilise CMHTs.	Quantitative, Interviews using instruments, n=180	Continuity of care is a key concept in the delivery of mental health care. This was defined as: experience and relationship, regularity, meeting needs, consolidation, managed transitions, care coordination and supported living.	Moderate: Clear aims and objectives which were mainly achieved by the report
Catty et al. (2012) UK	Mental health service users who utilised CMHTs.	Quantitative, Survey, n=93	The therapeutic relationship between the key worker and the service-user is a strong indicator of attachment to the CMHT.	Moderate: Clear aims and objectives. Methods section was clear and complete
De Burca et al. (2010) Ireland	Service users and Service providers who utilise and work in CMHTs	Mixed Methods n=738 survey of CMHT members Profiling study of 75 CMHT n=12 Focus groups n=10 Service user groups n=11 case studies n=23 local health manager Analysis of secondary data.	79% were satisfaction was recorded about access to the team, 85% were satisfied with the level of information on medications and in 75% of cases service-users and their team were in agreement with their diagnosis. Staff report resources are limited. Some clinical improvement was noted by a small sample of service users.	High Well written with an extensive method section. Various data collection methods. Clear aims and objectives which were achieved by the report.

Study	Participants	Interventions	Results	Quality Assessment
Elstad and Eide, (2010) Norway	Service users who utilise community mental health services.	Qualitative, interviews, n=10	Service users and providers need to be more involved in the care planning process.	Moderate: The methods and report achieved the aims of study
Gale et al. (2010) UK	Service users who utilise community mental health services.	Qualitative, Focus groups, n=12	Poor communication between primary care and mental health services was reported. Paternalism and poor structures exist in the health services.	Moderate: Methods and results sections were clear and achieved its aims
Gallagher et al. (2010) UK	Service users who utilise community mental health services.	Qualitative (pilot study), Interviews, n=10	Participants felt stigmatised from a mental health diagnosis. Trust in service providers was cited as important.	Moderate: Study achieved it aims. Caution required as it is a pilot study
Gilburt et al. (2008) UK	Service users admitted to an inpatient unit.	Qualitative, Interviews, n=19	Companionship to service users was deemed as important. The need for peer support in acute services was evident.	Moderate: Detailed results and the study achieved its aims
Hopkins et al. (2009) USA	Service users expectations of inpatient care	Literature review 10 papers.	Service users expected to feel in a safe place, have a relationship with Service providers and participate in talking therapies.	Moderate: Methods section limited. Results achieved study's aims
Jespersen et al. (2009) Australia	Data of service users from Primary Mental Health Teams (PMHT)	Quantitative survey of 153 referral forms & 89 assessment records	Characteristics of persons who utilise the primary mental health service were identified. Referrers overestimated risk and poorly diagnosed depression and personality disorders. More females than males utilised PMHTs	Moderate: Limited sample (1 PMHT records audited). Detailed results
Jones and Crossley (2008) UK	Service users and Service providers in acute units.	Qualitative, Focus groups, n=24	An acute unit admission can have negative consequences emotionally for service users who reported a loss of self-worth and adulthood.	Moderate: Results described well and clear methods
Jones et al. (2009) UK	Service users and carers who utilise CMHTs	Qualitative: longitudinal n=31	Service users found transitions in care and changes in staff stressful. Transitions i.e. admission/discharge need better management	Moderate: Limited methods section.

Study	Participants	Interventions	Results	Quality Assessment
Jones et al. (2010) UK	Service users admitted to an acute unit.	Qualitative, Interviews, n=60	Service users felt safe but some experienced threats and bullying.	Moderate: Methods and results sections were clear and well written. Study achieved it aims
Kovandzic et al. (2010) UK	Service users who accessed primary mental health services.	Qualitative. Case study, n=33	The need for support i.e. transport, financial throughout the treatment process was emphasised.	Moderate: Secondary analysis of qualitative data. Study achieved its aims
Meagher et al. (2008) Ireland	Case notes of Service users who utilised a CMHT.	Quantitative, Survey, n=504	The study outlined those who engage with a CMHT, the duration of treatment and data on caseloads. 53% of the population was female. 91% of service users received medications and 62% received shared care by the team. Average duration in service was 6.1 years.	Moderate: Limited sample (1 CMHT). Clear methods and results sections
Mental Health Commission (2011) Ireland	Survey of service users who were admitted to an acute unit.	Quantitative, Survey, n= 710	The study found 53.4% were appointed a key worker and 55.4 % had a care plan.75.2% of participants agreed their care plan was recovery focused. Over half of service users believed their complaints were not listened to.	High: Robust methodology, large sample size and study achieved its aims.
Mgutshini (2010) UK	Service users and Service providers in community mental health service.	Qualitative phenomenological study: Phase1 n=56, Phase 2 n=24, Phase 3, n= 22	Service users identified situational circumstances to readmission while Service providers identified medical factors leading to readmission of a service-user.	Moderate: Results were detailed and clearly written.
Morphet et al. (2012) Australia	Service users and carers who utilised emergency departments.	Mixed methods n=67 Survey, n=16 focus groups	Just half were satisfied with their experience. Professionals did not always listen to service-users	Moderate: Clear methods but small sample for survey.

Study	Participants	Interventions	Results	Quality Assessment
National Collaborating Centre for Mental Health (2012) UK	Service users experiences of care	Systematic Literature Review.	Greater involvement of service users in the planning and education of mental health professionals was recommended. Care plans should be jointly developed and be accessible to service users. Better communication is required in the mental health services.	High: Detailed and robust methods and comprehensive results
National Service User Executive (2009)Ireland	Service users who have utilised the Irish mental health service.	Mixed Methods, Survey, n=536	52% satisfied with the overall service. 58% of service-users felt listened to and 43% believed their views/wishes were given priority. 57% felt they were treated with dignity	Moderate: Limited data on methods. Clear results
National Service User Executive (2010) Ireland	Service users who have utilised the Irish mental health service.	Mixed Methods, Survey, n= 1,054	Result broadly similar to the previous year's survey. 57% satisfied with the services. Recovery model poorly understood.	Moderate: Limited data on methods. Clear results
National Service User Executive (2011)Ireland	Service users who have utilised the Irish mental health service.	Mixed Methods, Survey, n= 1,549	75.9 % were happy with the overall service. Staff attitudes and communication highlighted as issues of concern.	Moderate: Limited data on methods. Clear results
National Service User Executive (2012) Ireland	Service users who have utilised the Irish mental health service.	Mixed Methods Survey, n=1,488	78.4% were happy with the overall service. 50.3% had direct involvement in their care plan. 82.5% believed they are making progress to recovery. A lack of activities and treatment choice were cited in the report.	Moderate: Limited data on methods. Clear results
Newell et al. (2011) UK	Service users admitted to acute units.	Quantitative: cross sectional design Questionnaire, n=55	Participants with depression were most prone to boredom. Boredom was not linked with age, length of stay or gender.	Moderate: Questionnaire not validated for population
Nolan et al. (2011) UK	Service users admitted to acute units.	Qualitative: interviews n=44 inpatient n=18 final interview	Isolation was experienced post discharge by service users	Moderate, differences in collection of interview data i.e. face to face and telephone

Study	Participants	Interventions	Results	Quality Assessment
O'Regan and Ryan (2009) Ireland	Service users who utilised emergency department psychiatric services	Quantitative: postal questionnaire, n=55	The participants reported positive feelings regarding staff but dissatisfaction with ward environment	Moderate: Small sample. Uncertainty on who completed the questionnaire
Storm and Davidson (2010) Norway	Service users and Service providers in inpatient services.	Qualitative, interviews, n=20	Service users and service providers had different views of the inpatient experience. Professionals were nice but service-users opinions were not always heard	Moderate: Clear methods and results. Study achieved it aims
Sweeney et al (2012) UK	Service users who utilise CMHTs.	Mixed methods Survey/interviews, n=167	Service users need information on how to successfully navigate the mental health services while receiving care.	Moderate: Results clearly defined & it achieved the study's aim
Tanskanesn et al. (2011) UK	Service users and carers who tried to access psychiatric services	Qualitative Interviews n=30 n= 21 Service-users n= 9 Carers	Stigma and not recognising a mental health problem were major barriers to seeking help	Moderate: Sample from a single geographic area. Clear methods and results.
Taylor et al. (2009) UK	Service user views of clinical services	Systematic review 31 papers.	Service users experienced poor communication and staff demonstrated poor knowledge of self-harm.	High: Robust and clear methods. Results presented well
The Care Quality Commission (2009) UK	Service users who utilised inpatient mental health services.	Quantitative, Survey, N > 7,500	38% were offered talking therapies. 16% of participants feel unsafe during the admission. 40% were definitely involved in their care. 26% had more than one care plan review while 29% had one review	High: Robust methods Large sample Results well presented
The Care Quality Commission (2011) UK	Service users who utilised community	Quantitative, Survey N>15,000	Similar findings as 2008. Similar findings as in 2008. 83% of service-users were aware of their care co-ordinators. There was an increase in the numbers who	High: Robust methods Large sample Results well presented

Study	Participants	Interventions	Results	Quality Assessment
	mental health services.		did not know their care coordinator from 10% in 2008 to 12	
The Care Quality Commission (2012) UK	Service users who utilised community mental health services.	Quantitative, Survey N>17,000	Similar findings as 2008 and 2011. Service users wanted greater involvement in their care.	High Robust methods Large sample Results well presented
The Healthcare Commission (2008)	Service users who utilised community mental health services.	Quantitative, Survey N>14,000	Service users were mainly satisfied with the service. Service users demonstrated knowledge of the service and wanted greater involvement in their care.	High: Robust methods Large sample Results well presented

Acknowledging a mental health problem and seeking help

For many, the first experience service-users' have of mental health services, is when they are in crisis and seeking to access the service. Seven articles relating to accessing mental health services were found from the following countries, the United Kingdom (UK) (n=3), Ireland (n=2) and Australia (n=2). The methodologies utilised by researchers were three quantitative reports, three qualitative, one literature review and one mixed methods study.

Acknowledging that an individual is experiencing a mental health problem was the first issue that arose. Seeking assistance is complex and involves deliberately not looking for help, due to a number of issues or not recognising that help is required. People who did not acknowledge their difficulties suffered in silence and consequently their efforts to seek help were more complex and prolonged (Tanskanen et al. 2011) (n=62). A lack of knowledge regarding the clinical manifestations of mental health problems and the accessibility of the service was also a factor in determining a prolonged lead in time to accessing services. Stigma was acknowledged by Tanskanen et al. (2011) qualitative study as a barrier to accessing treatment which affected the whole family and how their community viewed them.

Some people may access mental health services through the emergency department. O'Regan and Ryan's (2009) quantitative study with 55 participants suggests that, whilst people with mental health problems may be treated kindly, issues arose around the environment and the knowledge staff had regarding mental health issues. Taylor et al. (2009) systematic review of 31 papers identified that some service-providers may have poor knowledge of self-harm.

The first response of service-providers to service users' is vital, as openness is required according to Kovandzic et al. (2011). Negative experiences of service-providers attitudes along with not being listening to were documented by Tanskanen et al. (2011) and Morphet et al. (2012). Once a person had begun accessing services further barriers, presented themselves such as transport, finances and support during the treatment process (Kovandzic et al. 2011). Meagher et al. (2009) survey of 504 case notes and Jespersen et al. (2009) survey of 153 referral forms and 89 assessment records, both concluded that more women than men access community mental health services.

In summary, accessing mental health services can be affected by a number of issues. Service users may fail to acknowledge or identify they have a mental health problem. Identifying a mental health problem is complex and may be due to lack of knowledge about their condition, the availability of mental health services and stigma. Practical issues such as, transport can affect the use of services. Service providers may need to consider whether obstacles exist which may prevent those who need services from coming forward.

Building relationships through participation in care

This theme highlights the disparities which exist in how service users and service providers perceive their relationship. Building relationships is recognised as an important tenet in meeting the service users' needs and facilitating participation in their care. Furthermore, the theme illuminates the difficulties and barriers in facilitating this process.

Twenty-one studies from a range of countries identified issues around relationships between service users and service providers (UK n=12, Ireland n=6, USA n=1, and Norway n=2). Of the twenty-one studies, eight were quantitative, six qualitative, five mixed-methods and two were literature reviews.

Commonly, studies reported on the importance of building relationships between the service users and the service providers in order to meet service users' needs and expectations (Arbuckle et al. 2012 n=24, Catty et al. 2012 n=93, Gale et al. 2012 n=12, National Collaborating Centre for Mental Health 2012). Hopkins et al (2009), in their review of ten studies, found that therapeutic relationships were not always evident within the mental health settings. Being valued and connected to staff and peers was an important component of the service users treatment programme (Hopkins et al. 2009). In addition, Arbuckle et al (2012) and Catty et al. (2012) found that the relationship between a service-user and a key worker was central to service users' connection with their CMHT.

Service users expressed difficulties in building relationships with service providers and this can be limiting to their participation in their care. The difficulties ranged from unsupported attitudes of service providers to inadequate communication about their treatment (The National Service User Executive (NSUE) 2009-2012). Within the inpatient settings, relationships between service users and service providers were driven by power and lack of choice. In a study conducted in the UK, Gilburt et al. (2008) interviewed patients (n=19) who highlighted that some staff employed the use of coercion. Service users' reported that fear was an element of their relationship with staff. Other concerns expressed by the patients were limited information on medication, lack of choice of treatment, restricted freedom and violence on the ward. Threats and coercion were cited as influences which inhibited the service-users' role in the decision making process (Storm and Davidson 2010). In another qualitative study, participants expressed the need to trust service providers when providing new information such as a new mental health diagnosis (Gallagher et al. 2010).

Nevertheless, a majority of participants (57%) felt their psychiatrist listened to them, while 48% of participants felt that nurses always listened to them according to the CQC inpatient quantitative study (2009). Engagement can be difficult as service-users and service-providers can have differing viewpoints. An example of this disparity was demonstrated in Mgutshini's (2010) qualitative study. From the service providers' viewpoint rehospitalisation was centred on medical problems such as non-concordance to medication, whilst service users concerns were focused on the psychosocial factors which they experienced prior to readmission.

However, some service users reported positive experiences. For example, half of the respondents in the 2012 NSUE survey felt that service providers' attitudes were changing. Of those, 60% felt that staff attitudes were changing for the better while 36% stated the shift in attitudes was a mix of positive and negative. Service-users have become more aware of the structure of community services and are increasingly engaging with them, for example in 2008 the CQC reported that 74% of respondents knew their Care Co-ordinator, while 85% were aware of their Care Co-ordinator in 2012. The Irish MHC (2011) reported that 81% of participants had access to a member of staff at all times and 87% of participants reported that they trusted their healthcare team.

The CQC and the Healthcare Commission annual surveys of CMHTs on inpatient services showed greater service-user involvement in the care planning process. These surveys had substantial numbers of participants (2008 N >14,000, 2009 N=7,500, 2011 N >15,000, 2012 N >17,000). The CQC (2009) inpatient survey found that 34% of participants stated they were involved in the decisions about their care, while 40% reported they were involved to some extent in the decision making process and 27% responded 'no' to the question. In addition, the CQC (2012) CMHT survey found that 54% of service-users believed their views were taken into account during their treatment and 43% of service-users acknowledged their goals were included in their care plan. In contrast, participants in Storm and Davidson's (2010) Norwegian qualitative study reported their input in the decision making process were not taken into consideration although the service providers showed kindness in their care. In the Irish context, De Burca et al. (2010) reported 64% of service-users understood and were satisfied with their care plan while 75% of service-users were aware of their treatment review. The qualitative study by Elstad and Eide (2009) with ten participants outlined the need for service-users to be fully involved in the care planning process.

Activities as part of the treatment programme were sometimes limited. Newell et al. (2011) quantitative study (n=55), found that boredom in acute psychiatric units plays a significant part of the inpatient experience. Participants questioned how therapeutic the activities were, while others described an obligation to join in ward based activities (Storm and Davidson, 2010). Additionally, the CQC's inpatient survey (2009) identified that 24% of participants believed there were enough activities available during weekdays, however these were reduced during weekends. The level and choice of activities are important issues for services providers to consider.

In summary, building relationships is an important element in the service users treatment programme. Service users expect and want to have good interpersonal relationships with service providers. Relationships are the basis on which participation in care may be realised. The relationship between both parties can be at times unequal with limited opportunities for service users to feel that their concerns are taken into account. The relationship between service users and providers remain ambiguous as existing data do not suggest how these relationships are or should be constructed in practice.

Working towards continuity of care

This theme illustrates the challenges faced by services users as they navigate the services during their mental health care journey. Continuity of care is a key component in the delivery of mental health care.

Eleven articles discussed continuity of care and its impact on service users. However, five of the articles were also referred to in the previous themes (CQC 2012, NSUE 2012, MHC Ireland 2011, De Burca et al. 2010, Storm and Davidson 2010).

These included four qualitative, three quantitative studies and three mixed methods.

Sweeney et al.'s. (2012) mixed methods study (n=167) outlined the preconditions to continuity of care in CMHTs. These were; easy access, the availability of the services and adequate information about the service. Furthermore, Burns et al.'s (2009) quantitative study with mental health service users (n=180), defined the concept in terms of experiences, relationships, regularity of meetings, addressing needs, consolidating care, managing transitions, co-ordinating care and supported living. A lack of continuity in care leads to feelings of loneliness, isolation and less opportunities for service-users to contribute to their care plan (Nolan et al. 2011). Jones et al. (2009) stressed that service users experienced social vulnerability when they were not supported in navigating social services such as benefits, housing and employment. This had a negative impact on how service users perceived continuity of care.

The system of care which aims to provide seamless care to service users' has been assessed by various researchers. According to MHC Ireland survey (2011), over half of the study's population were assigned a key worker (53.4%) with 55.4% having had a care plan completed. Less than thirty per cent of service-users (29.9%) could not remember a care plan being drawn up for them during their inpatient stay. In addition, 52% of complaints made by service-users were not satisfactorily dealt with from a service-user perspective. Service users were dissatisfied with the care planning process (Storm and Davidson 2010, Nolan et al. 2011). A new process in which service users participate in their care plan is being introduced to enhance service user participation in their care. The CQC (2012) found that 33% of service-users' were involved in more than one care plan review in 2012 compared to 26% in 2008. The numbers of service-users' who had no care plan review meeting dropped from 45% in 2008 to 38% in 2012. Despite this improvement, the number of service users who did not understand their care plan increased from 8% in 2008 to 9% in 2012.

The consequences of becoming a mental health service user may not be seen as a positive for some. Some service users experienced shame and a loss of adulthood when admitted to an acute ward (Jones and Crossley 2008). Nevertheless, satisfactions with the services were at moderate levels. The MHC Ireland (2011) reported that just over 84% of participants were satisfied with the inpatient service and 73% reported some improvement in their health status. Over 75% agreed their care was recovery focused while 82.5% believed their length of stay in hospital was appropriate. The majority of participants in the qualitative reports by Jones et al. (2010) and Nolan et al. (2011) felt stressed and isolated upon discharge from the acute setting. De Burca et al.'s (2010) mixed methods study found 79% of service-users were satisfied with their access to the CMHT. 67% of service-users were content with the level of information provided during their first meeting and 85% were satisfied with the length of appointments. In relation to perceived clinical improvements; 77% of service-users perceived improvements in family relationships, while 56% experienced improved social functioning and 70% reported increased self-confidence. The results regarding perceived improvements must be treated with caution as only 91 service users were involved to this aspect of the study. Finally, the NSUE

(2012) mixed methods study found that 78% of service users' were generally satisfied with their service.

In summary, continuity in care is recognised as an important goal however these findings suggest that the reality falls short of expectations in this regard. Continuity in care covers both health and social issues for many people with mental health problems. The limited number of key workers and completed care plans suggests the concept of continuity of care remains a goal yet to be achieved.

Discussion

This integrative review has analysed the findings of 34 articles and has identified three key areas that impact on service users and providers. These include; continuing concerns relating to stigma, the relationship aspects of care, service-users involvement in care planning and issues which impact on continuity of care.

Stigma was identified as a finding of this review. It can affect potential service-users by postponing access to services as participants identified shame, loss of adulthood and a sense of personal failure that resulted from being admitted to an inpatient setting (Jones and Crossley, 2008). Corrigan (2004) previously identified that stigma hampers the ability of people to access the service and how they interact in the treatment process. Whilst, this is not a new observation it is important for it to be reiterated in the context of involvement in the care planning process (Frank and Glied 2006).

The lack of service-user involvement in the care planning process emerged and continues to be an issue of concern. These concerns stemmed from the limited opportunities reported by service users to express views about their care needs and what should be included in their care plan. Where this was achieved, service users' involvement could be tokenistic (McDaid 2006). Tait and Lester, (2005) observe that service-user involvement is rarely implemented even though, many policies advocate it. Furthermore they argue that service-user involvement as outlined in mental health policies has little meaning in practice. A further reason for poor care planning is provided by Gould (2012) who suggests that, recovery in mental health is inadequately defined and service-users and providers are working towards different visions of what recovery means. In order to achieve a shared vision, good relationships and excellent communication are required.

Service-providers need to reflect on their communication methods as the recovery approach challenges current professional behaviour and advocates changing from ‘being an expert’ to a ‘coaching approach’ (Slade, 2009). There exists little research on how service-users wish to engage with service-providers and how these relationships can be established from a service-user perspective. Service-users reported the kindness of service-providers however, Swinton (2013) advocated that the mental health services, in particular the forensic services, need to move beyond kindness towards compassion. Compassionate and dignified care is central tenets in health care as identified by Francis (2013).

The Sainsbury Centre for Mental Health (2008) argues that the recovery approach demands a change of culture and a redrawing of the service-users role to emphasise personalisation and choice. There is convincing evidence that service-users wish to be more involved in their care planning process. Unfortunately, this may not be happening with limited involvement in care planning reported in some instances (MHC 2011). Furthermore, treatment choice, one of the main tenets of the recovery model (The Sainsbury Centre for Mental Health 2008), was reported to be lacking (CQC 2012).

It is beyond the scope of this paper to provide a critique of the recovery model however, there are a number of reasons as to why its implementation is limited including, staff resistance to change (MHC Ireland 2008 and Tait and Lester 2005), a lack of resources (O’Regan and Ryan 2009) and the unavailability of services (Tanskanen et al. 2011). Without adequate resources it is difficult for service providers to offer different pathways to recovery, consequently the status quo may remain. In order to facilitate a recovery based service Slade et al. (2012) highlighted the scale of the challenge that services now face. These include society’s poor understanding of mental illness and the expectation that services should manage risk and provide social control. The barriers to the recovery model may provide some rationale for the stigma, poor continuity of care and care planning process experienced by service-users’ throughout the mental health service.

Three literature reviews, conducted between 2008 and 2012, are included in this review (Hopkins et al. 2009, Taylor et al. 2009 and National Collaborating Centre for Mental Health, 2012). Taylor et al (2009) reviewed mental health service users’ experiences of accessing Accident and Emergency units. Hopkins et al (2009) reviewed mental health service users’ expectations of their care. Whilst the scope of the National Collaborating Centre for Mental Health (2012) systematic review is more reflective of this review they differ in emphasis. The review conducted by the UK National Collaborating Centre for Mental Health was more focussed on how the services work rather than the relationship aspects of care which emerged as central to the findings of this review.

The findings presented here build on these previous reviews by taking a holistic approach to the review of service users experiences and looking across services. This has facilitated further explication of issues linked to relationships, decision making and care planning and continuity of care.

In summary, this integrative literature review adds to the current body of knowledge by outlining the experience service-users have of the mental health service. This integrative literature review identified issues centring on service-users reluctance to use the service; the importance of relationships and the impact of these on continuity of care and differing levels of service-user involvement in their care. Despite the implementation of new models of care delivery such as the recovery model, the envisaged transformation of the mental health services has not yet been fully achieved from a service-user perspective. The implementation of these new models of care need to be reconsidered to ensure that the necessary reforms are completed with the service-user's voice heard throughout the mental health service.

Implications for Practice

The findings suggest that changes are required from the service-users perspectives. Stigma and an information deficit were encountered by service-users prior to meeting mental health professionals. This could be addressed by adopting a public health approach. This would help communities understand mental health problems, outline what services are available and empower communities to support those with mental health issues. This requires health care professionals to work in, and with communities. Innovative approaches are required to ensure service users are participants in their own care.

Community and in-patient mental health services face similar issues around fragmented care planning systems. Operationalizing aspects of the recovery model may address some issues around service user involvement in the care planning process. Addressing such issues at the level of the individual is important but limited. Service-users also need to be involved in the evaluation and development of services. This may be facilitated through service-user forums/representation on management councils to help service planners to interpret policy recommendations.

Limitations

Many of the included studies in this integrative review originated from the UK and Ireland. Whilst this review reflects developments in mental health services internationally, it may affect the generalizability of the findings. A decision was made to conduct an inclusive review which covered inpatient and community services. Challenges exist in synthesising the findings of a disparate range of studies. We presented a robust and transparent approach to this review and consistent messages emerged around the relationship aspects of care thus adding to the credibility and generalizability of the findings.

Conclusion

Implementation of the recovery model in clinical practice appears to be limited and its full potential has yet to be realised. A paradox exists between levels of satisfaction expressed through large scale surveys and issues around coercion, poor communication and a lack of involvement in treatment choices for people with mental health problems. The relationship aspects of care, require further investigation to ensure mental health services assist service users' recovery. A fundamental shift is required in the mental health provider – service user relationship in order to incorporate service users' participation and involvement in their care.

References:

Arbuckle R, Berry K, Taylor JL, et al. (2012) Service user attachments to psychiatric key workers and teams. *Social Psychiatry and Psychiatric Epidemiology* **47**, 817-825.

Burns T, Catty J, White S, et al. for the ECHO Group (2009) Continuity of care in mental health: understanding and measuring a complex phenomenon. *Psychological medicine*, **39**, 313-323.

Campbell P. (2005) From Little Acorns – The mental health service user movement, Available; www.centreformentalhealth.org.uk/.../mental_health_service_user_movement .pdf [accessed 12 Dec 2014].

Catty J, Cowan N, Poole Z, et al. (2012) Attachment to the clinical team and its association with therapeutic relationships, social networks, and clinical well-being. *Psychology and Psychotherapy: Theory, Research and Practice* **85**, 17-35.

Corrigan P. (2004) How stigma interferes with mental health care. *American Psychologist* **59,** 614.

De Búrca S, Armstrong C and Brosnan P. (2010) *Community mental health teams determinants of effectiveness in an Irish context:* Health Systems Research Centre, Limerick.

Department of Health (2001) *The journey to recovery- the government vision for mental health care.* Available: http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4058900.pdf [accessed 14 May 2013].

Dunne EA (2006) *The Views of Adult Users of the Public Sector Mental Health Services.* Available: www.mhcirl.ie/File/viewsadultspublic.pdf [accessed 12 Dec 2014].

Elstad TA and Eide AH. (2009) User participation in community mental health services: exploring the experiences of users and professionals. *Scandinavian Journal of Caring Sciences* **23**, 674-681.

Epstein RM and Street RL. (2011) The values and value of patient-centred care. *The Annals of Family Medicine* **9**, 100-103.

Francis, R. (2013) *Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry*, London, The Stationary Office.

Frank RG and Glied SA. (2006) *Better but not well: Mental health policy in the United States since 1950.* JHU Press, Baltimore.

Gale C, Baldwin L, Staples V et al. (2012) An exploration of the experience of mental health service users when they decide they would like to change or withdraw from prescribed medications. *Journal of Psychiatric and Mental Health Nursing* **19**, 853-859.

Gallagher A, Arber A, Chaplin R et al. (2010) Service users' experience of receiving bad news about their mental health. *Journal of Mental Health* **19**, 34-42.

Gilburt H, Rose D and Slade M. (2008) The importance of relationships in mental health care: A qualitative study of service users' experiences of psychiatric hospital admission in the UK. *BMC Health Services Research* 8, 92

Gould D. (2012) Service users' Experiences of Recovery under the 2008 Care Planning Approach. Available: http://www.mentalhealth.org.uk/content/assets/PDF/publications/CPA_exec_summary.pdf [accessed 21 Mar 2014].

Hopkins J, Loeb S and Fick D. (2009) Beyond satisfaction, what service users expect of inpatient mental health care: a literature review. *Journal of Psychiatric and Mental Health Nursing* **16**, 927-937.

Jespersen S, Chong T, Gray K, et al. (2009) Clinical characteristics and patterns of referral to a primary mental health team: A retrospective study. *Asia-Pacific Psychiatry* **1**, 81-87.

Jones A and Crossley D. (2008) 'In the mind of another' shame and acute psychiatric inpatient care: an exploratory study. A report on phase one: service users. *Journal of Psychiatric and Mental Health Nursing* **15**, 749-757.

Jones IR, Ahmed N, Catty J, et al. (2009) Illness careers and continuity of care in mental health services: a qualitative study of service users and carers. *Social Science & Medicine* **69**, 632-639.

Jones J, Nolan P, Bowers L, et al. (2010) Psychiatric wards: places of safety? *Journal of Psychiatric and Mental Health Nursing* **17**, 124-130.

Kovandžić M, Chew-Graham C, Reeve J, et al. (2011) Access to primary mental health care for hard-to-reach groups: From 'silent suffering' to 'making it work'. *Social Science & Medicine* **72**, 763-772.

McDaid S. (2006) *Equal and inclusive user involvement in the mental health services in Ireland: Results from participatory action research.* University College Dublin and Schizophrenia Ireland. Available at: http://www. ucd. ie/esc/html/shari_mcdaid. Pdf (accessed 7 Apr 2013).

Meagher D, O'Brien S, Pullela A, et al. (2009) Multidisciplinary activities in a community mental health service: relationship to Health of the Nation Outcome Scale scores and diagnosis. *Psychiatric Bulletin* **33**, 172-175.

Mental Health Act (2001), Dublin: The Houses of the Oireachtas.

Mental Health Act (2007), London: The Houses of Parliament.

Mental Health Commission (2011) *Your Views of Mental Health Inpatient Services.* Dublin: The Mental Health Commission.

Mental Health Commission (Ireland) (2008) *A Framework for Development A Recovery Approach Within the Irish Mental Health Services*. Dublin: The Mental Health Commission.

Mental Health Commission (MHC NZ). (1998) *Blueprint for mental health services in New Zealand: How things need to be.* Wellington: Mental Health Commission

Mgutshini T. (2010) Risk factors for psychiatric re-hospitalization: An exploration. *International Journal of Mental Health Nursing* **19**, 257-267.

Moher D, Liberati A, Tetzlaff J, et al. (2009) Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *Annals of Internal Medicine* **151**, 264-269.

Morphet J, Innes K, Munro I, et al. (2012) Managing people with mental health presentations in emergency departments—A service exploration of the issues surrounding responsiveness from a mental health care consumer and carer perspective. *Australasian Emergency Nursing Journal* **15**, 148-155.

National Collaborating Centre for Mental Health (2012) *Service user experience in adult mental health. NICE Guidance on Improving the Experience of Care for People using Adul*t NHS Mental Health Services. Available: http://www.nice.org.uk/guidance/cg136/resources/cg136-service-user-experience-in-adult-mental-health-full-guideline3 [accessed 13 Jun 2013].

National Service-User Executive (2009) *Second Opinions, Summary Report of the NSUE Survey of Members on Vision for Change.* Available: www.nsue.ie/m/uploads/files/Second_Opinions_NSUE_2009.pdf [accessed 30 Jun 2013].

National Service-User Executive (2010) *Second Opinions, Summary Report of the NSUE Survey of Members on Vision for Change.* Available: www.nsue.ie/m/uploads/files/Second_Opinions_2010_.pdf [accessed 30 Jun 2013].

National Service-User Executive (2011) *Second Opinions, Summary Report of the NSUE Survey of Members on Vision for Change*. Available: www.nsue.ie/m/uploads/files/SO2011.pdf [accessed 30 Jun 2013].

National Service-User Executive (2012) *Second Opinions, Summary Report of the NSUE Survey of Members on Vision for Change.* Available: www.nsue.ie/m/uploads/files/Survey_Members_2012.pdf [accessed 30 Jun 2013].

Newell SE, Harries P and Ayers S. (2011) Boredom proneness in a psychiatric inpatient population. *International Journal of Social Psychiatry* **58**, 488-495.

Nolan P, Bradley E and Brimblecombe N. (2011) Disengaging from acute inpatient psychiatric care: a description of service users' experiences and views. *Journal of Psychiatric and Mental Health Nursing* **18**, 359-367.

O'Regan C and Ryan M. (2009) Patient satisfaction with an emergency department psychiatric service. *International Journal of Health Care Quality Assurance* **22**, 525-534.

Rowe J. (2012) Great expectations: a systematic review of the literature on the role of family carers in severe mental illness, and their relationships and engagement with professionals. *Journal of Psychiatric and Mental Health Nursing* **19**, 70-82.

Sainsbury Centre for Mental Health (2008) *Making Recovery a Reality*. London: Sainsbury Centre for Mental Health.

SIGN, Harbour RT and Forsyth L. (2008) *SIGN 50: a guideline developer's handbook.* Scottish Intercollegiate Guidelines Network.

Slade M, Adams N and O'Hagan M. (2012) Recovery: past progress and future challenges. *International Review of Psychiatry* **24**, 1-4.

Slade M. (2009) *Personal recovery and mental illness: a guide for mental health professionals*. University Press, Cambridge.

Storm M and Davidson L. (2010) Inpatients' and providers' experiences with user involvement in inpatient care. *Psychiatric Quarterly* **81**, 111-125.

Sweeney A, Rose D, Clement S, et al. (2012) Understanding service user-defined continuity of care and its relationship to health and social measures: a cross-sectional study. *BMC Health Services Research* **12**, 145.

Swinton J. (2013) Beyond Kindness: The Place of Compassion in a Forensic Mental Health Setting. *Health and Social Care Chaplaincy* **1**, 11-21.

Tait, L and Lester H. (2005) Encouraging users involvement in mental health services, *Advances in Psychiatric Treatment* **11**, 168-175.

Tanskanen S, Morant N, Hinton M, et al. (2011) Service user and carer experiences of seeking help for a first episode of psychosis: a UK qualitative study. *BMC Psychiatry* **11**, 157.

Taylor TL, Hawton K, Fortune S, et al. (2009) Attitudes towards clinical services among people who self-harm: systematic review. *The British Journal of Psychiatry* **194**, 104-110.

The Care Quality Commission (2009) *National Results Tables: Mental Health Inpatient Survey Results 2009.* Available: http://www.nhssurveys.org/survey/1038 [accessed 1 Jun 2013].

The Care Quality Commission (2011) *Historical Comparison Tables: Community Mental Health Survey Results 2011.* Available: http://www.nhssurveys.org/survey/1086 [accessed 1 Jun 2013].

The Care Quality Commission (2011) *Monitoring the use of the Mental Health Act in 2009/10.* Available: http://www.cqc.org.uk/sites/default/files/documents/cqc_monitoring_the_use_of_the_mental_health_act_in_200910_main_report_tagged.pdf [accessed 12 Jun 2014].

The Care Quality Commission (2012) *National Summary of the Results for the Community Mental Health Survey 2012.* Available: http://www.nhssurveys.org/surveys/660 [accessed 1 Jun 2013].

The Healthcare Commission (2008) National NHS patient survey programme. *Survey of users of community mental health services.* Available: http://www.nhssurveys.org/survey/1045 [accessed 1 Jun 2013].

Whittemore R and Knafl K. (2005) The integrative review: updated methodology. *Journal of Advanced Nursing* **52**, 546-553.