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The position of carers in mental health care: Exploring
experience-based co-design

Section A: Can Experience Based Co-Design be the remedy
for the persistent lack of carer involvement within mental health
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Summary of Major Research Project

Despite mental health policies stipulating carer involvement, there has been limited action to successfully involve them. The project aimed to explore carer involvement within mental health services on both an individual and organisational level. A literature review found limited research on carer involvement and highlighted barriers to their involvement. Experience based co-design is a service design strategy to support the implementation of carer and service user involvement, has been posited as a means of bridging this gap. Reports of carer involvement have been inconsistent, and only one previous project has explored their experiences in a physical health setting. The current study produced a preliminary theory of the key processes involved in an EBCD project with families and carers within a mental health context. It proposed that efforts need to be made in setting up the project: ensuring that the project meets an organisational need, to ensure stakeholder buy in. Project facilitators need to be responsive to the relational elements throughout the process. Local leadership is essential for sustained involvement. Implemented solutions need to be simple and readily integrated into clinical practice. This theory is hoped to support future projects to achieve their potential, highlighting key processes involved for consideration.

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**Can Experience Based Co-Design be the remedy for the persistent lack of
carer involvement within mental health services?**

Abstract

Mental health care policy has made it a requirement that services actively involve service users and carers on a micro (individual) and macro (organisational) level. However, carers remain marginalised, reporting limited involvement. Experience Based Co-design is a service design strategy that utilises carer, service user and staff experiences to implement change.

Two questions were posed within the review: (1) what do we know about carer involvement in mental health care; and (2) what is the effect of implementing experience based co-design (EBCD) in mental health services. Separate searches were completed using ASSIA, PsychInfo, Medline and CINAHL to find relevant articles. Search terms were identified to maximise the number of relevant papers found. Each paper was assessed against exclusion criteria and quality measures. Twelve papers were included in the review. Papers were summarised under the separate questions and synthesised to give a clear summary.

Despite policy documents stipulating carer and service user involvement, limited research suggests translation of these requirements to action has not been achieved, leaving the potential for carer and user involvement unrealised. EBCD was positioned as a potential means of implementing meaningful carer and service user involvement. Future implications of this review are considered.

Key words

Carer involvement, care participation, experience-based co-design, adult mental health, mental health care

Introduction

Rationale for service user and carer involvement

Mental health care policy requires that services actively involve service users and carers on a micro and macro level, meaning active participation in decisions about individual care, service planning, evaluation, training and research (Cree, et al., 2015; DoH 2001, 2004, 2008). Valuing their expertise through experience and positioning service users as equal partners with professionals (Tambuyzer, & Van Audenhove, 2011). These documents assume the involvement of service users in service development will lead to improved outcomes; however, they do not specify how involvement should be implemented (Wilkinson & McAndrew, 2008).

The Carers Act (2004) and The National Carers Strategy (2008) provided formal recognition of the value of carers' involvement, as expert care partners, and highlighted the importance of staff considering their wellbeing. Carers rarely feature as a separate group within research and studies exploring involvement within mental health care (Bradley, 2015; Kara, 2013). However, carers provide their own distinct but often complementary contribution to these efforts (Kara, 2016). The limited focus on carers as a distinct group may contribute to the difficulties in implementing effective involvement within services.

Service user involvement

Crawford et al.'s (2002) literature review explored the impact of involving service users within a variety of physical and mental health settings in the planning and development of health care. A number of methods were employed: patient and staff interviews, patient surveys, consultation meetings with patients, as well as patient representatives and consumer committees. Outcomes included: improvements to service accessibility; improved information resources for patients; increased advocacy and improving employment opportunities; as well as an increase in favourable staff attitudes to involvement. Inconsistent accounts of service user

and staff experiences of involvement were recorded. Authors emphasised that involvement should not be used by providers to legitimise unpopular decisions (Crawford, et al., 2002).

Carer involvement

The term carer refers to someone who supports a person with mental health difficulties. This may be a family member, partner or friend (Karr, 2016). Carers are estimated to support 1.5 million individuals in the community, saving the health services between £119 million and £1.24 billion annually in nursing care costs (Cree et al., 2015).

Research supports their involvement, showing positive outcomes from carer involvement in an individual's care (De Civita, Dobkin, & Robertson, 2000). Collaboration between professionals and carers has been found to support the carer and foster more resilient coping through enhancing their knowledge and their sense of control and mastery (Wilkinson & McAndrew, 2008). However, carers report being insufficiently acknowledged, and frequently request greater access to information and communication between themselves and healthcare professionals (Stanbridge, Burbacj, Lucas & Carter, 2003).

Bradley (2015) completed an overview of the literature focused on co-production within mental healthcare in the UK. Co-production was defined as a process in which professionals, service users and carers plan and deliver improvements to a community's quality of life, based on the valuation of each perspective and a sharing of power. The review suggested limited involvement may be a result of professionals underestimating the value of carer involvement, with staff perceiving meetings as burdensome and time consuming. Carers were reported to have developed a sense of inferiority to staff, limiting engagement which may be perceived as acquiescent. Service user involvement was limited as a result of professionals being unwilling to trust patients' views and preferences, and divergent outcomes wanted by professionals and service users undermining the potential for co-production.

Prioritisation of the needs of the service, as defined by professionals, over the needs of carers and service users may have been borne out of a historically paternalistic model of mental health care. This approach ranked professionally informed knowledge and methods over knowledge gained through experience. These ideas are slowly being eroded from health services, but some persistent elements, such as compulsory detention, may contribute to the limited involvement of service users and carers in mental health treatment and service delivery (Munro, Ross & Reid, 2005).

Challenges to carer and service user involvement

It has been posited that the translation of policy documentation into practice has not been achieved (Bee, Brooks, Fraser, & Lovell, 2015). There is uncertainty around implementation and the outcomes expected (Rutter, et al., 2004), leading to the potential for user and carer involvement to remain unrealised (Lewis, 2014). Service user and carer involvement has previously been implemented in the form of one-off consultation, satisfaction surveys and complaints procedures (Boaz, et al., 2016). These methods of data collection, are not sufficient to deliver improvements to the quality of care (Springham & Robert, 2015). Survey data have been reported to be ignored by clinicians, whereas narrative methods provide richer data that can capture the interests of staff and other stakeholders (Coulter, Locock, Ziebland, & Calabrese, 2014).

Barriers to involvement have been found to be related to the cost of involvement, the perceived representativeness of service users and carers, and professional resistance (Tait & Lester, 2005). Carer and service user involvement can be limited by their need to actively participate within an unknown context, which uses technical language and has service specific protocols and structures (Lowndes & Skelcher, 1998).

Possible theoretical explanation for challenges

Research has found stigmatising attitudes are relatively high among mental health service staff (Nordt, Rossler, & Lauber, 2006) and families are often assumed to be the cause of service users' difficulties (Krupnik, Pilling, Killaspy & Dalto, 2005) and often accrue stigma by association (Corrigan & Miller, 2004). Stigma is also experienced by service users, who in the context of service delivery and involvement, must fight for the recognition of their cognitive capacity (Rutter, et al., 2004). These factors may impede collaboration.

Social identity theory (Tajfel & Turner, 1979) proposed individuals social identities are based upon group membership. This involves three mental processes: categorisation, identification and comparison. Categorisation enables us to understand our social world more readily, assigning people to categories that tell us something about one another. Identification results in adopting a group identity, which can influence behaviour in an attempt to conform to group norms. Comparisons are then made between groups with the subjective effect of bolstering self-esteem through the aggrandisement of our group. This theory has been supported by research, and has recently been used to shed light on applied topics, such as clinical domains (Haslam, 2014). Social identities and groups play a critical role in health and organisational outcomes, as self-categorisations shape people's responses within their given context (Haslam, 2014). Applying this theory to the mental health context, staff and service users form separate groups, who compete to maintain their preferred state of power.

Allport (1979) suggested that prejudices arise from ingroup-outgroup distinctions and inflexible generalisations, proposing that more positive attitudes towards out-group members can be formed through contact under optimum conditions:

Equal status contact between majority and minority groups in the pursuit of common goals [...] contact is sanctioned by institutional supports, and [...] leads to a perception of common interests and common humanity (Allport, 1979, pg 489).

A review by Corrigan and Shapiro (2010) of research into what works in reducing stigma, supported this hypothesis. Strategies that foster the development of collaborative working may need to ensure that common interests are the foundations for such work.

Experience based co-design

Use of patient experience was outlined as a key quality measure in the High Quality Care for All: The NHS Next Stage Review (Darzi, 2008), endorsing the need to enhance patients' experiences of care. A systematic review exploring the associations between clinical safety, effectiveness and patient experience, suggested experience is highly associated with better health outcomes, as well as patient safety and clinical effectiveness (Doyle, Lennox & Bell, 2013). Research has indicated a positive association between patient experience, staff experience and quality. Investment should be made to support staff welfare (Gasper, 2010) through positive working environments and engagement with staff around service provision (DoH, 2015).

Experience Based Co-Design (EBCD) (Robert, 2013) was developed within the NHS, to cultivate "incentive-driven" change. EBCD is a form of participatory action research, which seeks to understand individual experiences of health services and actively engage service users, carers and staff to facilitate co-design of improvements (Donetto, Tsianakas, & Robert, 2014). Unique in co-design and participatory research, EBCD has a clear framework and accessible set of guidelines (King's Fund, 2013) and this may be why it has been taken up with some enthusiasm. EBCD follows a six stage cycle: (1) setting the project up; (2) collecting staff experiences from interviews and observations; (3) collecting patient and carer experiences from

filmed interviews; (4) holding a joint event bringing both staff and patients and carers together, to share patient and carer films and identify priorities for change or emotional touchpoints; (5) co-design groups are established around priorities and sustained; and (6) a review event is held to celebrate the outcomes achieved.

Donetto and colleagues (2014) completed a study to explore how widely EBCD had been implemented, using an online survey and follow up interviews with practitioners who had completed an EBCD project. Only 70% of the 59 completed projects reported their outcomes; a high proportion are unavailable publicly. EBCD was found to have led to the implementation of small-scale improvements. Secondary benefits were reported: providing a space for service users, carers, and staff to work together, dispelling preconceptions, promoting an increased sense of mutual accountability and improving staff motivation for change (Boaz et al., 2016). This appears consistent with Allport (1975), and Corrigan and Shapiro (2010).

EBCD literature reported carer involvement inconsistently, some focusing on service user experiences alone (Bate & Robert, 2006) and others including carers (Wright nee Blackwell, et al., 2017). Omitting carers from EBCD would limit the diversity of perspectives and potentially limit the outcomes achieved. One project was completed to improve carer experiences on a chemotherapy outpatient setting (Ream, et al., 2013). This project resulted in the collaborative development of a DVD and leaflet. The impact was tested with a feasibility trial. Pre and post measures were completed by 43 carers, and found improvements in carer knowledge of chemotherapy and increased confidence in their supportive role, indicating that this approach can be used to improve care experiences (Tsianakas, et al., 2015).

Rationale for Literature Review

Policy documents insist on service user and carer involvement in all levels of mental health care (Wilkinson & McAndrew, 2008). Carer involvement has been linked to improved

outcomes for those receiving mental health services (Cree et al., 2015). However, carers are reported to experience dissatisfaction with their involvement (Stanbridge, et al., 2005). Limited literature for carer involvement leaves unanswered questions about carer involvement in services at present, and whether any means have been sought to support involvement within individual care and on an organisational level.

EBCD is a service development strategy, aiming to improve outcomes through collaboration between service users, carers and staff. EBCD projects were predominantly in physical health settings (Donetto et al, 2014). To expand upon how this approach can be adapted and utilised within mental health settings, the focus of this review is on projects within mental health care.

The aim of the current review is to explore:

What do we know about carer involvement in mental health care?

What is the effect of implementing EBCD in mental health services? Does this approach enable carer involvement?

Method

Databases and Search terms

Two searches were completed to address the review's aims. Each search used a number of databases: ASSIA, PsychInfo, Medline and CINAHL, to search for relevant literature.

Search terms and combinations were developed by the researcher, from an initial search using frequently used terms; supplementing this list with additional terms used within the literature, maximising the possible results available. Terms are displayed in the table below.

Table 1:

Display of search terms used within database for systematic review of literature

Search	Term 1		Term 2		Term 3		Term 4
Carer Involvement	Mental health care OR Mental health treatment OR Mental health intervention OR Mental health care design OR mental health care planning	AND	family involvement or carer involvement or spouse involvement or friend involvement	OR	family inclusion or carer inclusion or spouse inclusion or friend inclusion	OR	family participation or carer participation or spouse participation or friend participation
Experience Based Co-Design	EBCD	OR	Experience Based Co-Design	AND	Mental health care		

Duplications were removed from results. Abstracts were reviewed to assess relevance. Remaining articles were assessed for eligibility using specified inclusion and exclusion criteria and a quality assessment framework. The reference lists of relevant articles were checked for additional papers. Two flowcharts detail the method used (figure 1 and 2).

Inclusion Criteria

Articles were included within the current review if written in English, covering a range of geographical locations. There was no set time frame for the literature included. Both quantitative and qualitative research were included if they used a formal methodological design.

Articles for the carer involvement search were limited to those exploring carer involvement in mental health care, on either micro or macro levels, which occurred in adult mental health services. The means of involvement may be dissimilar across mental health services, and groups may experience different barriers to involvement.

Inclusion for EBCD articles was limited to projects within mental health services.

Exclusion Criteria

Articles were excluded from the current review if they were not set within mental health care settings. Papers were excluded if not specifically relevant to carer involvement in decisions about care and design (e.g. carer involvement within research and training).

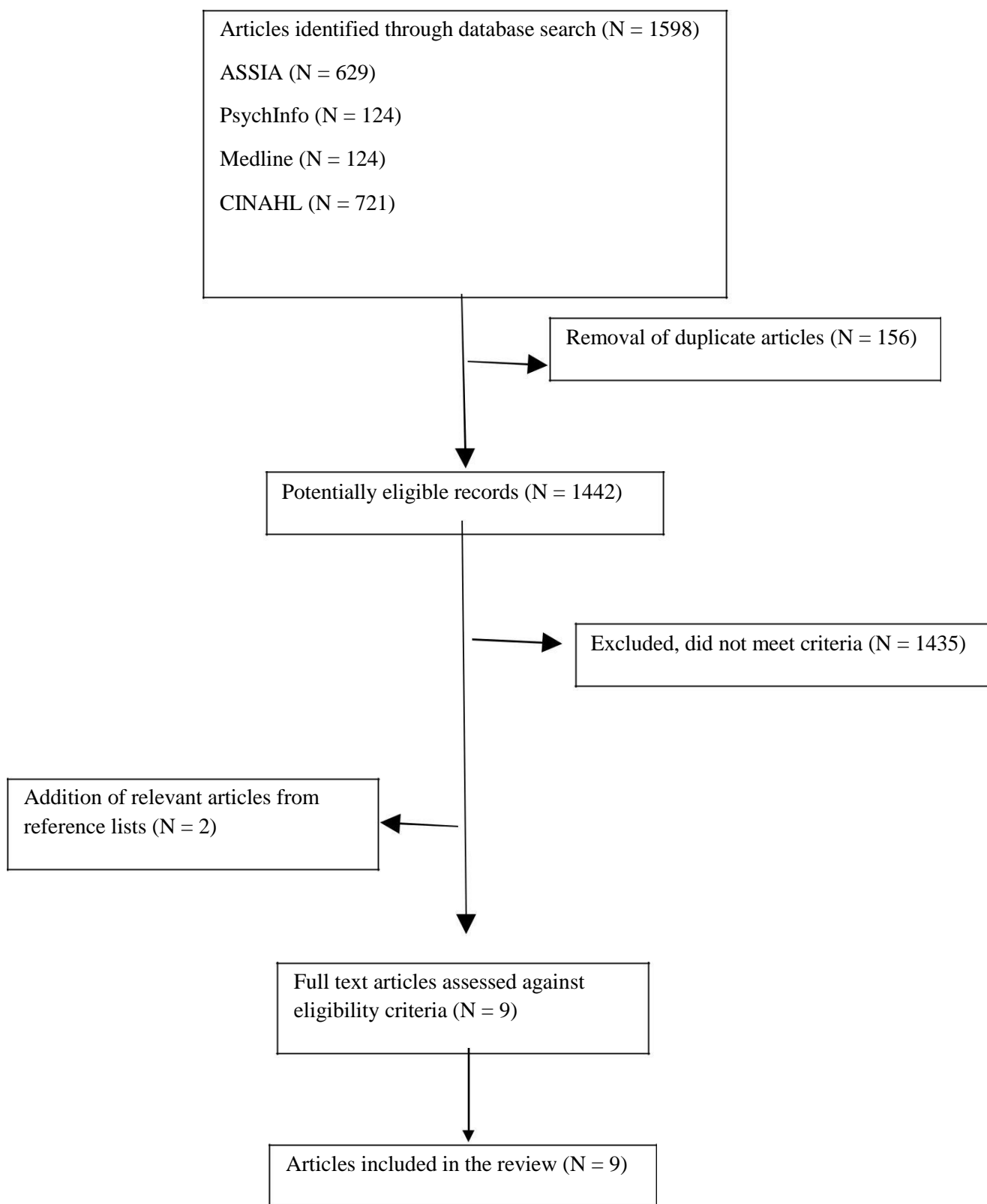


Figure 1: *PRISMA Diagram* (Moher, Liberati, Tetzlaff, & Altman, 2009) *delineating the search process for papers related to carer involvement*

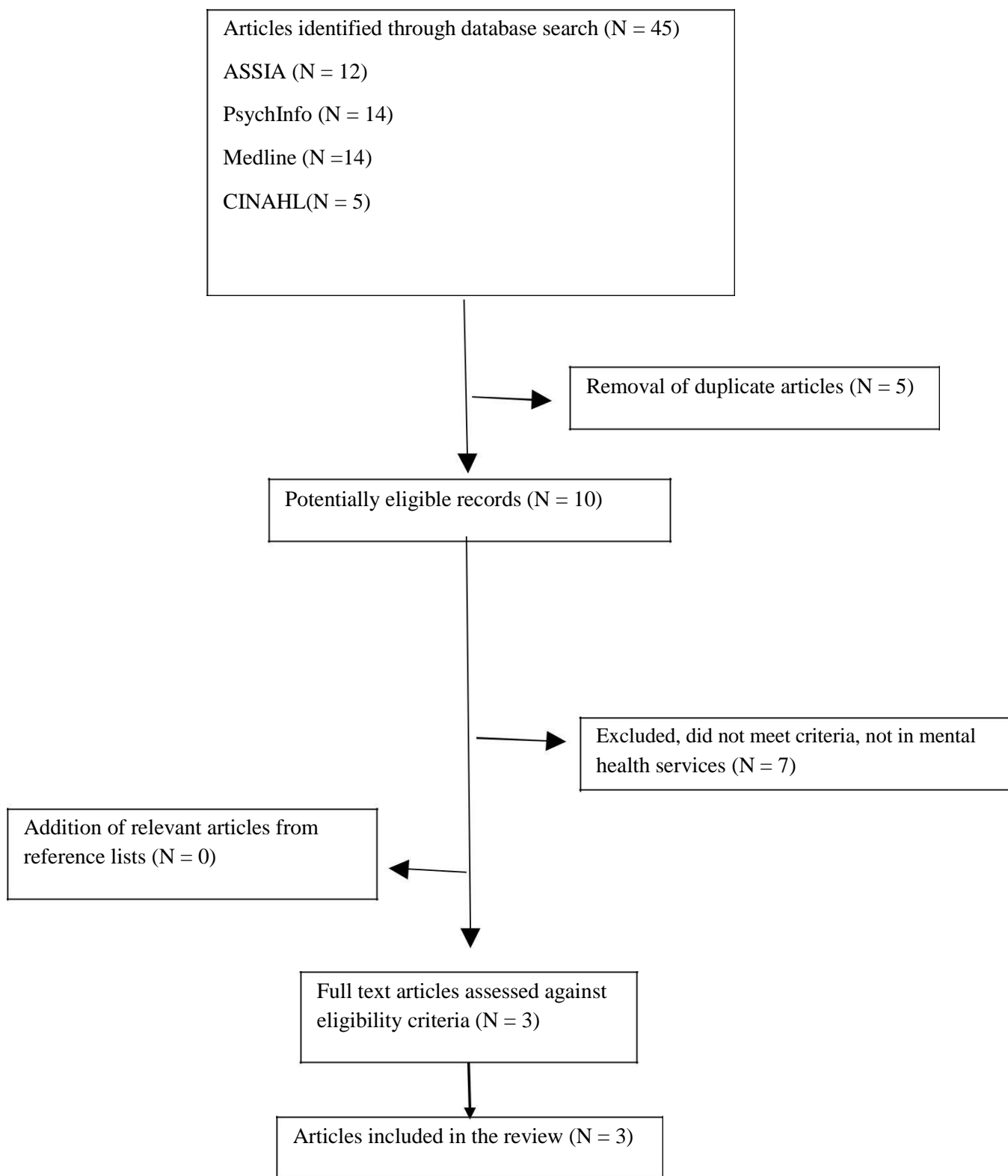


Figure 2: *PRISMA Diagram* (Moher, et al., 2009) delineating the search process for papers related to EBCD

Results

Twelve articles met eligibility for inclusion. Literature is presented under the separate review questions. Key themes were summarised to provide a concise description of findings. The Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields (Kmet, Lee & Cook, 2004) and Yin's criteria (2009) were applied to assess the quality of the research included within the review. Results are displayed in Appendix A.

What do we know about carer involvement in mental health care?

Nine articles were included within the review for carer involvement within mental health services. The literature encompassed carer involvement within micro and macro levels and has been presented within the review under these categories.

Carer and Service User involvement at a micro level

Six articles were reviewed at this level (Table 2). Wilkinson and McAndrew's (2008) phenomenological study aimed to explore the experiences of carers when their relative was admitted to an inpatient ward. Four carers volunteered to be interviewed. Four main themes were identified: powerlessness, needing to be recognised and valued, feeling isolated and a desire for partnership. Carers described a divide between professionals and themselves, with professionals holding all the knowledge and control, leaving them to take a passive stance. They raised a need to be supported and to be helped to understand what was happening, both in managing this admission and the future. They noted that professionals avoided engaging with carers and decisions that would impact on them directly were made without them, despite wanting to be involved. Carers wanted to be recognised as a source of knowledge but also as an individual experiencing emotional distress: The carers in the study experienced neither.

These processes could impact negatively on carers' wellbeing, self-esteem, and their ability to provide ongoing support. The authors stated that carers experienced a consumerist

approach to involvement, with participation relying on professional willingness to consider their views in decision-making, or information giving. The authors proposed not sharing information with carers disempowered them, enforcing professional control over decisions. For partnership to exist between carers and professionals a shift needed to be made in the balance of power, with an increased recognition of the expertise and knowledge held by carers. The authors acknowledged that what is an acceptable level of involvement will differ amongst carers, but that this is a conversation that is of importance. Care should be taken in generalising these results, due to the limited sample size.

Lakeman (2008a; 2008b) wrote two papers in the context of the development and introduction of practice standards for carer involvement. A steering group developed the standards from a range of community groups in Australia, with consultation with service users and carers. The standards outlined time frames for information sharing and involvement of carers, and mandated the question of whom should be involved in their care. A mental health nurse and a carer promoted and evaluated the practice standards.

One paper (2008a) aimed to establish the impact of the introduction of the practice standards on the quality of carer involvement, as well as carers' experience of involvement. The study completed random file audits, in community (pre = 25, post = 29) and hospital settings (pre = 30, post = 30), three months pre and post the introduction of the practice standards. A family questionnaire, developed by the steering group was used to capture key aspects of the practice standards 3 months post introduction. Simultaneously, three open ended questions about obstacles for involvement, perceptions of involvement and improvements. Descriptive statistics were used to analyse the data produced by the file audits (pre and post) and survey responses.

THE POSITION OF CARERS IN MENTAL HEALTH CARE: EXPLORING EXPERINCE-BASED CO-DESIGN

Table 2:

Carer and Service User involvement at a micro level

Author	Location	Aim	Participants	Method	Analysis	Main findings	Strengths	Limitations
Wilkinson, & McAndrew, 2008	UK	Explore perceived level of involvement from perspective of carers of SU who were admitted to acute inpatient setting	Four carers (two spouses and two mothers) Service users that had not been on a ward for 2 years	Interviews	Phenomenological enquiry	4 themes: powerlessness, feeling isolated, needing to be recognised and valued, and desire for partnership	Researchers considered four criteria of rigour. Data collection and analysis was clearly documented.	Small sample size
Lakeman, 2008 (a)	Australia	Determine whether or not the introduction of practice standards made a difference to the level and quality of carer participation.	Inpatient participants: 41 consumers and 27 carers Community participants: 86 consumers and 33 carers	Audit of hospital and community files (55 pre and 59 3 months after introduction) Survey of carer and consumer perspectives of quality (following the introduction of practice standards)	Descriptive and inferential statistics	Increased contact with carers Consumers and carers generally satisfied with involvement of carers in mental healthcare Modest agreement that mental health workers consulted families or carers	Data collection and analysis was clearly documented.	No comparison data for the survey, as no pre introduction data for the survey. Hawthorne effect, impact of being observed. Potential bias in auditing data, auditor involved in call for practice standards No data collected about quality of contact. No information in relation to sustained change Limited data presented about analysis completed.

THE POSITION OF CARERS IN MENTAL HEALTH CARE: EXPLORING EXPERINCE-BASED CO-DESIGN

Author	Location	Aim	Participants	Method	Analysis	Main findings	Strengths
Lakeman, 2008 (b)	Australia	To explore the perceptions of service users and carers participation in adult mental health services	129 service users (41 hospital sample and 86 community group) 86 family members (53 hospital sample and 33 community group)	Survey: questions around obstacles to family participation, perceived benefits, and areas of improvement	Summative content analysis	Obstacles to involvement: distance, language barriers, lack of family understanding, communication difficulties. Contradictions about helpfulness and feeling involved, want to be involved? A common thread – need for basic respectful engagement and ready access to advice and help	Study design was appropriate. Sampling strategy appropriate.
Tambuyzer & Van Audenhove, 2011	Belgium	Assessed differences between service users, family carers' and mental health care providers perceptions on service user and carer involvement in mental healthcare	111 service users, 73 family carers, and 216 mental healthcare providers Members of a care network for people with serious and persistent mental illness	Questionnaires	Descriptive analysis and Wilcoxon Two-sample test	Service users and professionals perceive family carer involvement as less important and realised that service user involvement Service user and family involvement not reaching potential	All three stakeholders – direct comparison Questionnaire developed from literature review

THE POSITION OF CARERS IN MENTAL HEALTH CARE: EXPLORING EXPERINCE-BASED CO-DESIGN

Author	Location	Aim	Participants	Method	Analysis	Main findings
Bee, Brooks, Fraser, & Lovell, 2015	UK	Explore professionals' perceptions of delivering collaborative mental health care planning and involving SU and carers	51 Multi-disciplinary professionals involved in care planning	Focus groups and 28 interviews across two NHS sites	Framework Analysis (Ritchie and Spencer, 1994)	<p>Emergent themes:</p> <p>Care planning meaningful platform for involvement.</p> <p>Tensions between involvement and accountability.</p> <p>Staff relational skills as a facilitator for involvement.</p>
Cree, Brooks, Berzinz, Fraser, Lovell & Bee, 2015	UK	Explore carers' experiences of mental health services and the care planning process	37 carers and 3 service users	5 Focus groups and 26 interviews	Framework Analysis (Ritchie and Spencer, 1994)	<p>Perceive a lack of involvement, lack of recognition and appreciation of their roles</p> <p>Barriers: structural, timing, location, cultural (power imbalances, confidentiality)</p>

Results from the hospital audit suggested no significant differences between service user characteristics pre and post practice standard introduction. There was a modest increase (14%) in carer participation in care plans in the post introduction group. There was an increase in family contact and the number of contacts listed, though not significant. There was a significant difference in the number of examples of family involvement in treatment planning, with an increase post introduction, and a significant increase in carer contact with doctors. The result from the community audit suggested some differences in patient characteristics between pre and post introduction groups. Modest but not significant improvements were found in reports family contact, and family contacts related to treatment planning. No data were presented about carer contact with individual professional groups. Documentation in community files was poor, whilst improvements had been made to inpatient files. Both community and hospital files focused on symptoms and crisis events over social factors. The inconsistent use of statistical analysis limits this section of the report.

Forty-one inpatient service users and 27 carers completed the family participation survey. There was no significant difference between responses from carers and service users, and no significant correlations between the responses. There was a weak relationship between carer responses to items, despite heterogeneity in their responses. Carer satisfaction with involvement was positively correlated with: perceptions of being consulted, 'perceptions that mental health workers were interested in what they had to say', 'receiving detailed information about illness', and 'questions being answered satisfactorily'. Eighty-six community service users and 33 carers completed the survey. Service users who agreed to carer contact were significantly more satisfied with the family involvement provided. No further statistics were supplied for this sample.

There were no significant differences reported between responses for families and carers in the hospital and community samples. A high proportion of service user (inpatient =

78%, community = 77%) and carers (both settings =70%) were satisfied with the level of carer participation. However, only 52% (on ward) and 61% (in community) of carers reported that they were consulted about care and treatment. The highest scores across both settings and respondent groups, was in response to the item “family and carer involvement enhanced care and treatment”.

The audit suggested that modest improvements had been made within carer involvement in both settings. Despite the ease with which the standards could be implemented there was inconsistent implementation. Survey data could not be used to infer impact of the introduction of the practice standards but suggested that carers and services users were happy with the level of involvement they received. Sustainability of improvements beyond the initial three months required further exploration. The results of these data may be limited by the Hawthorne effect, in which participants change their behaviour when being observed. There was a potential bias in the analysis of the documentation data, as researchers were invested in the practice standards implementation.

Data collected from the open ended questions were analysed using summative content analysis (Lakeman, 2008b). Respondents reported a number of obstacles to family involvement: distance from services, lack of family understanding, poor communication, waiting time, being satisfied with services, need for independence/personal choice, the well-being of family, and the person’s condition or behaviour. A higher proportion of carers (62%) in the community setting reported no obstacles to involvement, than in the ward setting (39%). A number of themes were suggested in relation to respondents’ views of how family participation helped, including: provision of support, facilitating/accessing care, and working as a team.

Respondents gave a number of responses to how carer participation could be improved, including: improve sharing of information, increasing access to family, improve family functioning, improve adherence to treatment, and improve services generally. Suggested across the data was a need for respectful engagement, and ready access to help and advice. Recommendations for enhancing family participation arose from service users' views that their family did not understand their difficulties. The range of responses from families and carers suggest that simplistic classification and prescription is not feasible; service users, and carers have different but related support needs, depending on a number of factors, for example, familiarity with mental health system, and the severity of the problem. Arguably, mental health services need to shift focus from medical treatment to more emotional, practical and material support for families and carers. The author stated family requests were unremarkable but essential for their ability to support service users (Lakeman, 2008b).

Tambuyzer and Van Audenhove (2011) reported questionnaire data that assessed the differences between service users', carers' and professionals' perceptions of key aspects of service user and carer involvement in mental healthcare. The questionnaire was developed by the researchers, based on a literature review on service user and carer involvement. Items assessed the degree of perceived importance and the degree of perceived realisation: 'to what degree is this realised'. Respondents were invited to complete the questionnaire by care network coordinators, and were members of sixty-one care networks in Belgium. Selection criteria were applied to service users and carers. Data included in the results were collected from 111 service users, 73 carers and 216 providers. Descriptive statistics were used to present questionnaire findings.

Overall, stakeholders appeared to perceive involvement as important, although they emphasised different priorities. Service users and carers valued providers creating opportunities for involvement, being treated as an equal conversation partner, and enabling

collaborative treatment decisions, as well as being provided with relevant information and documents. Providers prioritised offering tailored information to service users and valuing service user strengths and weaknesses. Service users and carers felt that their priorities were being matched in practice. This was reflected in higher rated realisation scores. However, this was not mirrored in the provider's reports of involvement in these areas. The authors suggested that differences in stakeholder perspectives may result from an underestimation of information and participation needs of service users by providers. Providers reported service user involvement was more important and more realised than carer involvement. The findings suggest that there is still room for improvement in meeting service users' and carers' needs for involvement. This project was completed in Belgium and care should be taken when generalising findings to the UK, due to different health care systems and political pressures.

Cree and colleagues (2015) conducted interviews and focus groups with carers to investigate experiences of participating within mental health services and care planning. The results indicated that carers had a clear understanding of a "good care plan" and how this was to be achieved. Carers stated an ability to bring "objectivity" to care plans when it was felt that an unclear picture was being given to staff by services users. Carers were able to support the development of a care plan that focused on the individual as a whole, which is often missed by professionals under time constraints.

Generally, carers reported negative experiences: not being involved in development or invited to meetings, and care plans were lost within other administrative tasks. It was felt that care planning perpetuated top down risk averse cultures and reaffirmed the traditional boundaries placed around service user and carer roles. All carers called for greater consultation between carers, service users and staff, with improved transparency and communication. Professionals being seen as 'experts' and carers seeking permission to participate in decision-

making, limited involvement. It was felt that rebalancing power differentials and time spent developing relationships with carers would improve information exchange.

Carers cited confidentiality as a barrier to involvement, suggesting absence of professional understanding led to misuse and the exclusion of carers from discussions. One suggestion made by the carers was for an independent mediator to be involved during times of conflict and disagreement. The authors concluded that carers reported a lack of involvement, alongside a lack of recognition for their role and the value of their involvement. Carers stated that successful involvement included good relationships, effective communication, sufficient time for explanations and partnership working; and could result in greater service efficiency, direct service user support, improved service user understanding and professional communication.

Bee and colleagues (2015) aimed to explore mental health professionals' experiences and perceptions of involving service users and carers in decisions about their care. They completed 28 interviews and four focus groups across two NHS trusts. Many of the professionals involved advocated for service user and carer involvement, and perceived their involvement to confer multiple benefits when care planning, as well as improving relationships, reducing power differentials and improving the quality of care offered. They reported it was often difficult to put into practice within traditional models of accountability, with responsibility placed solely on frontline staff, and the ensuing fear of litigation because of breaches in confidentiality. This was further compounded by ill-conceived notions of feasibility, high workload pressures, and organisational cultures of limited training and support. There was a mismatch in priorities raised by staff between meaningful involvement and the need for cost-effective and efficient healthcare. The authors concluded that collaborative working was supported on ideological grounds, but barred by conceptual and operational processes. They stated that for involvement to become routine practice they need to be

supported by organisational structures. Their purpose and benefits need to be understood by all involved, and staff need to feel confident and skilled. This research may be limited by the focus on staff responses which may be subject to social desirability bias. Authors acknowledged that this could be combated with ethnographic observations.

Summary

The studies covered a range of stakeholder perceptions of service user and carer involvement in mental health services. All papers reported that there was value in carer involvement within care, including improving quality of care and the quality of relationships within care.

There were inconsistent findings in relation to carers' and service user's perceptions of their involvement in mental health care. Two papers reported carers were not sufficiently involved, with a lack of recognition for the value of their involvement (Cree et al., 2015; Wilkinson & McAndrew, 2008). Two other papers reported they were satisfied with their level of involvement (Lakeman, 2008a, 2008b; Tambuyzer & Van Audenhove, 2011). The range of responses from families and carers suggest that simplistic classification and prescription of support is not feasible (Lakeman, 2008b). It was suggested that successful involvement required good relationships, effective communication, sufficient time for explanations and partnership working (Cree et al., 2015). Barriers were perceived to be perceived power differentials, limited understanding of confidentiality, work load pressure and organisational culture (Bee et al., 2015).

Professional perspectives were considered (Bee et al., 2015; Tambuyzer & Van Audenhove, 2011). One paper suggested that staff supported collaborative working on ideological grounds, but felt hampered by conceptual and operational processes, such as notions of feasibility, pressured workloads and limited training and support (Bee et al., 2015).

Another suggested carers and service users had distinct priorities from staff for involvement, which led to an underestimate of the value placed on carer and service user priorities (Tambuyzer & Van Audenhove, 2011). For involvement to be implemented routinely, it needed to be incorporated in feasible tasks within daily practice (Lakeman, 2008a), with staff understanding its purpose and benefits (Bee et al., 2015).

Carer and Service User involvement at a macro level

Three studies reported involvement at a macro level (Table 3). An action research study was implemented in an English mental health trust, to integrate service user and carer views on implementing self-directed support (SDS). SDS is intended to offer greater informed control over the support offered to those receiving services. Co-researchers (2 service users and 2 carers) worked alongside the lead researcher, gathering data from focus groups, meetings, and steering group meetings alongside professional staff. Qualitative data were transcribed and thematically analysed. Co-researchers were recruited through job advertisement, and engaged in qualitative research methods training. Safeguards were in place to support them throughout, including debriefing sessions and one-to-one meetings. A steering group was established, recruiting staff from the local services, management and finance. All decisions were discussed and agreed in this forum. Two papers were published (Hitchen, et al., 2011; Hitchen, & Williams, 2015).

Table 3:

Carer and Service User involvement at a macro level

Author	Location	Aim	Participants	Method	Analysis	Main findings	Strengths	Limitations
Hitchen, Watkins, Williamson, Ambury, Bemrose, Cook, & Taylor, 2011	UK	Describe learning gained from involving service users and carers as researchers in an action study.	Three service users, and two carers	Data collection: debriefing meetings with co-researchers between April and December 2007; a group interview held by the lead researcher, and participants journal comments and reflections	Use of a coding scheme on common data categories revealed by reading transcripts	Barriers to involvement: professional language barrier, emotional impact, and power imbalances between themselves and professionals.	Appropriate data collection methods and analysis	Limited sample size impacts generalisability
Hitchen, & Wiliamson, 2015	UK	Discuss learning about service user and carer involvement from an action research study into self-directed support implementation in an UK based mental health trust.	Four co-researchers: two carers and two service users	Data collection: focus groups, training sessions, and other meetings and attending collaborative steering group meetings alongside professionals	Thematic analysis	Successful action research requires: clear recruitment strategy, formal appointment and support structures of co-researchers. Democratic means for all stakeholders to be involved in change Benefits from service user and carer involvement: empowering service users, adding authenticity, shared learning between service users, carers and professionals.	Clear research objective	Data collection and analysis was not clearly documented.

Author	Location	Aim	Participants	Method	Analysis	Main findings	Strengths	Limitations
Horrocks, Lyons, & Hopley, 2010	UK	Examine the evidence from service user and carer involvement at board-level to support the idea that involvement will lead to better outcomes	132 service users and carers	Postal questionnaire and review of documents from: service user and carer group minutes, Lancashire Partnership Board (LPB) agenda, annual action plans generated, and LPB minutes	Thematic analysis	<p>Key themes identified within questionnaire: family and friends, work and activity, having control, being treated with respect, and quick access to support.</p> <p>Key themes in documentation: processes and actions, giving information, involvement of service users and carers, commissioning issues, service and workforce.</p> <p>Service user and carer representation did not lead to better outcomes for service user and carers. Limited time was spent addressing their priorities and limited action was taken in response to concerns.</p>	Use of triangulation of results from questionnaire data and document data	Report did not include any raw data from questionnaire as evidence of coding, making it difficult to understand key themes.

Hitchen and Williams (2015) reported learning gained from service user and carer involvement. They reported difficulties that arose within the project, including: co-researchers' difficulties in understanding nuances and acronyms used in the meeting, and inconsistent trust representation slowing the process. Attempts to mitigate these difficulties were put in place, including ground rules, but did not solve these problems. Data analysis was shared between co-researchers, but held by the main researcher, enabled new researchers to participate. Co-researchers were given authentic roles, with job applications and pay. The authors stated that co-researchers gained an understanding of organisational processes and became an effective voice for influencing the organisation's decision making. Their engagement within the project led to a sense of empowerment, and further employment for a co-researcher. Their engagement facilitated co-learning, with the lead researcher seeing issues with a fresh understanding gleaned from their shared experiences. The authors indicated that communication, power and emotional factors were important for consideration in involving service users and carers in projects. They highlighted the importance of recruitment, formal appointment and support structures in the form of debriefing meetings and preparatory sessions, as important mitigating factors. This paper is limited by its partial documentation of the analysis and results.

Hitchen and colleagues (2011) aimed to understand involvement from a service user and carer perspective. Data were collected from six debriefing meetings, a group interview and written comments and self-reflections; and analysed using a coding scheme. Three key themes emerged: communication, emotional content and power relations. All participants reported that the language used within meetings was problematic: impacting the engagement process, slowing the progress of service user and carer contribution to meetings, and disempowering participants who reported feeling that they appeared stupid if they did not understand. Background information was helpful for co-researchers to understand the context, as well as group rules to initiate an awareness of the language used.

Emotional content was the core contribution of co-researchers, drawing on their own experiences to support the development of solutions. However, the emotional effect of their involvement was felt to be undervalued by professionals. Carers reported ‘inhabiting different worlds’ in which carers returned to their caring role and professionals went home at the end of the day. The authors stated the use of emotive language needs to be at the forefront of involvement, as emotions have been found to be motivators and pervasive influencers of behaviour and beliefs.

Finally, power relations were noted by co-researchers. It was reported that some professionals held a ‘tick box attitude’, undervaluing the richness gained from multiple perspectives, which led to a sense of inequality and lip-service being paid to true involvement. The authors suggested large mental health organisations unavoidably employ those with disempowering attitudes, but a culture needs to develop that encourages openness to involvement.

The limited sample of carers and service users involved in the project may impede generalisability but reflects the reality of their representation at board level.

Horrocks and colleagues (2010) aimed to explore the assumption that service user and carer involvement in planning, design and commissioning mental health services led to better outcomes, by examining board-level service user and carer participation in a Lancashire mental health trust. Data were collected from 103 postal questionnaires, to assess carer and service user priorities in relation to the promotion of mental health and wellbeing within the trust. A review of documents, including service user and carer group minutes, Partnership Board (PB) agenda and minutes, and annual action plans was performed.

The questionnaire highlighted family and friends being the most important priority for service users and carers, with work activity, control, being treated with respect, and quick

access to support following. This data were then used for comparison with the data collated in the documentation. Themes were identified from the document data: partnership board processes and actions, giving information, involvement of service users and carers, commissioning issues, service and workforce; and included the service user and carer priorities. The most frequently appearing theme was processes and actions, followed by the other document-generated themes. Of the 4 document types, only 1 referred to all 5 service user and carer generated themes and that was infrequently. Service user and carer issues appeared low priority at board level. Concerns raised by carers and service users within the meetings were tracked: 2 were responded to with direct action, 1 was met with support and advice outside the meeting, 1 raised a sympathetic response but was deferred, and 2 did not result in any conclusion.

The authors suggested carers and service users had limited success in representing their interests at board level, as the majority of meeting time was devoted to trust processes. The researchers suggested service user and carer representatives were expected to ‘get up to speed’ with the culture and norms of the trust systems, placing them at a disadvantage. Service user and carer representation at board level could indicate a commitment to their involvement, however, it does not necessarily result in their meaningful involvement. The authors proposed that involvement does not lead to better outcomes for all, but indicates a need for involvement to evolve further.

Summary

The papers explored service user and carer involvement at an organisational level. Two papers (Hitchen et al., 2011; Hitchen, & Williamson, 2015) described involvement within an action research study, and indicated that involvement could be experienced as empowering for those involved within the project. This lead to the development of new skills and understanding of the organisational process. Staff gained a new understanding of the difficulties faced by

carers and service users. The authors stipulated a need for clear roles, training and support for carer and service user representatives to reduce power imbalances present.

Meaningful involvement was inhibited by language barriers; a lack of recognition of the emotional impact of their involvement; limited respect for the value of emotional input and power differentials. This was supported by the final paper (Horrocks, et al., 2010) which indicated that for meaningful involvement, the means of implementation need to evolve. They suggested that the needs of the organisation outweighed those of service users and carers, with limited action being taken to address their priorities and concerns. This finding indicated involvement can be symbolic and not represent a change in organisational behaviour.

Experience Based Co-Design

Three articles were related to EBCD within mental health services (Table 4). Larkin et al. (2015) completed an EBCD project in an early intervention in psychosis team. This project began with a research project exploring the experience of hospitalisation from the perspectives of service users, families and professionals, across two hospitals in the Midlands. The findings were translated into ‘touchpoints’ that could be used within an EBCD project, following consensus being reached by the project stakeholders (150 service users, carers and staff). A touchpoint is any factor that makes a difference to someone’s experience of the service (Robert, 2013), and usually has an emotional tone. Steering groups, consisting of service users, carers and staff, were used to continue to monitor and implement the action plans. At publication, some actions had been implemented, but none were reported.

Table 4:

Review papers describing experience based co-design in mental health services

Author	Aim	Participants	Method	Analysis	Main findings	Strengths	Limitations
Larkin, Boden, & Newton, 2015	Described how three qualitative research studies exploring the perspectives of service-users, parents, and staff about hospitalization in early psychosis were translated into service improvements developed in collaboration with a range of stakeholders, including service-users, carers, community and inpatient staff, and management	Staff members, service users and carers (not specified)	Case study Mixed-method design using interviews, focus group and analysis of complaints data. Followed the EBCD process partially (no filming).	Not specified	No detailed account of outcomes. However, suggested some successful implementation. Extension on the project to action further plans.	Utilised findings from a research project to provide evidence base for touchpoints.	No outcomes to report in relation to the goals.
Springham, & Robert, 2015	Explore the high levels of formal complaints received by the service from service users and families	Staff and 6 service users from an inpatient ward	Case study Mixed-method design using interviews, focus group and analysis of complaints data. Followed the EBCD process.	Not specified	Reduced complaints Development of DVD	Highlighted important considerations for future EBCD projects within mental health.	Sustainability of outcomes not maintained. Limited impact beyond those involved in the project.

Author	Aim	Participants	Method	Analysis	Main findings	Strengths	Limitations
Cooper, Gillmore, & Hogg, 2016	Explore the challenges faced when implementing this approach within this setting	Staff and 6 service users from a psychological therapies service	Case study Mixed-method design, using interviews, focus group and survey. Followed the EBCD process.	Not specified	No outcomes related to the SMART goals decided upon within the study. Positive experiences expressed by service users involved in the process.	Highlighted important considerations for future EBCD projects within mental health.	No outcomes to report in relation to the goals. Limited service user's involvement beyond identifying SMART* goals.

**SMART goals stands for Specific, Measurable, Achievable, Realistic and Time-based.*

There were plans for an extension and re-audit in 12 months. The authors suggested easily implemented changes were readily executed within the service, however, difficulties were met when improvements required external input. When changes were not implemented, stakeholders were left feeling disappointed.

This paper highlighted the potential for distress following the retelling of service user's stories, which was addressed through offering contact details for named facilitators. They highlighted the importance of anonymity within EBCD when considering the legacy of EBCD films. Due to the emotive nature of the films, the authors censored narratives to ensure the message was clearly put across without dramatisation.

The authors called for further instruction within the EBCD toolkit for the implementation stage of the project. All stakeholders needed to be committed to the shared narrative for successful implementation; if the organisation is not behind the project, the project cannot fulfil its potential. They suggested that the research evidence provided in this study was supportive in acquiring organisational interest. Staff turnover and instability within the service can impact on the project's sustainability (Larkin et al., 2015).

Springham and Robert (2015) followed the EBCD protocol detailed by the King's Fund (2013) to explore the high levels of formal complaints received by the service from service users and families. Touchpoints were established by service users, carers, and staff, from the experiences shared within the joint event. These were consolidated to inform decisions upon key areas to take forward and develop actions within the improvement process. The paper highlighted the importance hearing each group, as staff and service users highlighted different priorities. For example, service users prioritised relational elements of care, whereas staff focused on care plans. Co-design teams were created to continue to monitor and implement the

action plans. The service users involved within the project were recruited from an established service user group, which acted as a support network for other service users.

Following the intervention the ward experienced 23 months without any formal complaints, which contrasted with two similar wards within the trust. The project led to significant transformations within the running of the ward, including the abandonment of a pre-existing triage system and the development of a 'welcome to the ward' DVD. It was recognised that the approach achieved more than actionable design strategies but also experiential learning and awareness for staff. Ward staff reported the significance of the films and co-production in changing their working practice and the recognition that overly routinised work was contributing to professionals losing sight of the relational elements of their work. The authors highlighted the potential for power imbalances, as professionals can impact upon an individual's care and civil liberties.

Springham and Robert (2015) highlighted that EBCD is in its infancy and more research is required to explore the mechanisms involved in EBCD to increase the likelihood of success in future projects and to improve the sustainability of identified changes. They also suggested future projects should look beyond the scope of complaints as a measure of impact.

Cooper et al. (2016) completed an EBCD project within a psychological therapies service and followed the EBCD protocol (Kings Fund, 2013). Service users, and staff members came together to share experiences, in order to develop SMART goals (Doran, 1981) for service improvements around key touchpoints. The authors stated that prior to the joint event, service user's experienced high levels of anxiety around being judged for their views. It was noted that this dissipated when staff viewed the videos in the presence of the service users, which enabled a more cooperative approach to be taken, facilitating joint working. Service user and carer involvement ceased after this point, as clinicians involved in the project were

allocated a goal and a deadline for completion. This was due to limited resources at this point of the project. At the time of publication, there were no outcomes, however, progress was being made.

The authors suggested that the project facilitated a space for service user voices to be genuinely heard and there was a belief that the goals produced would lead to positive outcomes within the service. Feedback questionnaires were used, and indicated that service users had a positive experience participating in the project and felt respected and listened to.

The EBCD process requires commitment to achieve the goals set out within the process. In the current context of restricted resources, implementing service development may not be prioritised, despite the political pressure to involve service users. Additional barriers raised were; the high levels of support required by service users to participate; the reluctance of staff to participate in an equitable way (for example being filmed at the interview stage as were service users); and the sustainability of changes made. They were also concerned about the representativeness of their co-design, suggesting EBCD may only be accessible to a certain sample of carers and service users.

The authors suggested that future projects explore how to support staff and foster confidence within the process, so that equality can be reached in participation. They also highlighted the lack of acknowledgement of change cycles within the EBCD methodology, which may suggest the need for frequent repetition to sustain improvements that would be costly.

Summary

The projects indicated EBCD can result in the implementation of co-designed outcomes, which can significantly impact clinical practice. The authors reported secondary

outcomes, where service users experienced being heard and valued and staff recognised a need to change their practice. A number of factors inhibit successful implementation, including: limited resources, trust support, staff turnover, and staff confidence in involvement.

Adjustments by the authors to make EBCD applicable to mental health services, recognised the different ethical and practical considerations involved. For instance, service users required support throughout their involvement, and considerations about anonymity.

The authors suggested that future research was required to explore the mechanisms involved in EBCD, its implementation, and how outcomes can be sustained over time. Each project was conducted differently, highlighting the flexibility of EBCD, but also limiting the generalisability of findings across projects.

Discussion

Policy documents requiring the involvement of service users and carers have not specified how involvement should be implemented (Rutter et al., 2004). Limited literature available may be the result of services not reporting their involvement in public forums; a lack of carer involvement due to confusion regarding implementation (Rutter et al., 2004); or researchers not distinguishing carers as a separate but distinct group from service users (Kara, 2016). Only two papers focused on carer perspectives alone (Lakeman, 2008a; Wilkinson, & McAndrew, 2008).

Literature exploring carer and service user involvement in individual care, ranged from collecting different stakeholder perspectives of involvement to the introduction of practice standards to implement carer involvement. The key findings suggested inconsistencies in carer perspectives on their involvement. Two papers indicated that carers were not involved and required greater recognition for their knowledge (Cree et al., 2015; DoH 2001, 2004, 2008; Wilkinson & McAndrew, 2008), and two papers indicated carers were satisfied with their level of involvement (Lakeman, 2008a; Tambuyzer & Van Audenhove, 2011). These discrepancies may be the result of geographical variations between where the studies were conducted or the limited sample size. Furthermore, service users and carers perceived greater involvement than was mirrored in staff reports for performing on these factors (Tambuyzer & Van Audenhove, 2011). Carers and service users were found to have distinct priorities for involvement, which led to an underestimation of the value placed on carer and service user priorities by staff (Tambuyzer & Van Audenhove, 2011). Staff supported collaborative working, but were limited by notions of feasibility, pressured workloads and limited training and support (Bee et al., 2015). For involvement to be implemented routinely, it needed to be incorporated in feasible

tasks within daily practice (Lakeman, 2008a), with staff understanding its purpose and benefits (Bee et al., 2015).

Literature exploring involvement on a macro level, found that involvement could be empowering for those involved and promote a wider understanding for staff of the difficulties experienced by service users and carers (Hitchen, & Williamson, 2015). However, studies indicated that involvement could be symbolic and disempowering, particularly when involvement is impeded by language barriers, power differentials and continued focus on organisational needs. These findings suggested a need for a change in the implementation of involvement (Horrocks, et al., 2010). One paper suggested meaningful involvement could be facilitated by clear roles, training and support for carer and service user representatives (Hitchen et al., 2011).

Literature suggested that positive outcomes can be obtained by following EBCD, in the form of actionable improvement goals, attitudinal change and improved relationships (Cooper et al., 2016; Springham, & Roberts, 2015). EBCD developments are embedded within the service and directed by those using and working within the service that has been prepared for change within the investigative phases (Roberts, 2013) whereas improvements that come from above may start from a negative stance and are often not sustained (Walker & Dewar, 2001). EBCD may facilitate a space for involvement through the reduction of stigma between groups, by setting out clear goals and objectives, with organisational support, and valuing each stakeholder's perspective with equal importance (Allport, 1954). This possibly facilitates all stakeholders to engage and share their knowledge, improving motivation and empowerment from which sustained change can grow.

EBCD can fall into difficulty if not supported by sufficient time, resource, or organisational support (Cooper et al., 2016). Translating EBCD into mental health services has

been partially effective within the literature reviewed; adaptations were required, such as offering support to service users involved. Supporting research literature found carers required support and training to actively participate (Hitchen et al., 2015). EBCD may facilitate small changes within a service, which the service has a commitment to achieve, such as making a welcome film for new patients entering a ward (Springham, & Roberts, 2015). One of the research articles noted that for changes to be implemented, they needed to fit readily into daily practice (Lakeman, 2008b).

Future Research

The current review highlights the sparsity of research exploring the nature and impact of carer involvement in mental health care. This may be a result of carers being subsumed into service user literature, limited reporting of current interventions to involve carers on an individual and organisational level, or a continued focus on service user involvement alone. Carer representation at board level did not have an impact on outcomes (Horrocks, et al., 2010), whereas involvement in the participatory action research reported some impact (Hitchen et al., 2011). Papers reported a number of barriers to involvement. Future research is required to support the development of methods to improve carer and service user involvement at this level. EBCD may present a framework for this and has been used to support carer involvement within services (Tsianakas, et al., 2015). However, this project was completed in physical healthcare and so further research is required to explore feasibility in mental health services, where it has been suggested that carers are a marginalised group (Bradley, 2015). Two of the papers reviewed included carer experiences and resulted in successful outcomes (Larkin et al, 2015; Springham & Robert, 2015).

Further research to explore the mechanisms involved in facilitating change in EBCD. Research suggested that EBCD could be adapted to mental health services, there may be other

factors to consider; for example, how to facilitate greater staff engagement and confidence in the approach, and the need to provide sufficient information and on-going support for involved service users and carers – making them truly equal partners. Only a few EBCD projects had been done in mental health, leaving questions about whether change mechanisms are similar in physical and mental health care settings. A tentative theoretical mechanism has been put forward here, referring to Allport's contact hypotheses (1979), EBCD projects are highly complex, and it would be helpful to understand their modes of action more clearly, to maximise potential positive outcomes.

Conclusions

Policy documents stipulated the involvement of carers and service users on a macro and micro level (Cree et al., 2015; Wilkinson & McAndrew, 2008). From the limited literature it appears that this has not been translated into action, consistent with Rutter et al. (2004). There appears to be a need for service user and carer inclusion. Involvement at board and clinical levels should prioritise carer and service user needs over organisational needs (Horrocks et al., 2010), and limit the use of technical jargon (Hitchen, et al., 2011). EBCD has potential to provide a framework for involvement, with the potential to overcome such barriers by forging collaborative work around common goals. Further exploration is required to better understand this highly complex process.

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A Grounded Theory exploration of the processes involved in an Experience Based Co-Design project with families and carers in an Adult Community Mental Health Team.

Abstract

Experience Based Co-Design (EBCD) is a service design strategy that meaningfully involves service users and translates qualitative data into action. EBCD has not been applied within the context of designing family engagement within a mental health context, and there is little research exploring the mechanisms that ensure successful implementation. Therefore the aim of this project was to explore the processes that facilitate the EBCD work with carers and family involvement.

Sixteen participants were recruited from an existing EBCD project who reflected the multiple stakeholders. The study adopted a grounded theory approach and the interview data were analysed accordingly.

The preliminary theory produced offers an understanding of the processes involved within an EBCD project with carers, and can be used to inform the successful implementation of future projects. The preliminary theory suggests that for a project to be successful, it needs commitment from multiple stakeholder and leadership from both project facilitators and local and senior management. Once established, previously separate groups can work together towards a shared aim and develop simple solutions that can be easily implemented into clinical practice.

The EBCD project was not completed at the time of this report, and so may not reflect the end processes. Future research should be conducted to examine the impact of organisational disruption on the effectiveness of EBCD, by completing a project with this range of stakeholders in a more stable setting.

Key words:

Experience based co-design, Service user and carer involvement, Grounded theory, Mental health, Community mental health team

Introduction

NHS and Service Improvement

Policy documents mandated the involvement of service users and carers in service design (Cree et al., 2015; DoH 2001, 2004, 2008; Wilkinson & McAndrew, 2008), but have not expressed any guidelines for implementation (Rutter et al., 2004) resulting in the potential for involvement remaining unrealised (Lewis, 2014). Common means of facilitating user involvement have been satisfaction surveys, one-off consultation and complaints procedures (Crawford et al, 2002). This information has rarely been translated into service improvement (Coulter, Locock, Ziebland, & Calabrese, 2014). Barriers to involvement in service design have included: prioritising organisational needs over service user and carer need (Horrocks, Lyons, & Hopley, 2010), use of technical language, and professional attitudes towards involvement undervaluing the richness gained (Hitchen et al., 2011).

The aim of service redesign is to provide ‘better’ care for ‘users’ (Bate & Robert, 2006). The NHS traditionally focused on improving care by enhancing functionality (ensuring services fulfil their designated role) and safety (developing safety standards), ignoring usability (leaving users with a positive experience of a service) (Bate & Robert, 2006). To design services that are usable the design professions make users’ experiences integral to the development procedure. Forlizzi and Ford (2000) stipulated “we can’t really design an experience, only the mechanisms for creating it, and the interactive and expressive behaviours that modulate it” p3. A literature review, in physical health settings, suggested that patient experience is positively associated with the traditional measures of quality, clinical safety and effectiveness, supporting the use of experience to provide quality services (Doyle, Lennox, & Bell, 2012).

Experience Based Co-Design

EBCD is a form of participatory action research, which aims to engage those who use services and staff at “every stage within the design process, from problem diagnosis to solution generation and implementation” (Bate & Robert, 2007). The idea of ‘co’ in co-design, refers to the role of service users and professionals as shared leaders, moving service users to a position where they are actively contributing to designing care. EBCD follows a six stage process (Kings Fund, 2013) displayed in figure 1. The first stage involves gathering service user, carer, and staff experiences of the service via interviews and observations. Data collected are used to identify touchpoints; critical moments within an individual’s experience of a service. They usually have emotional connotations, which is what makes them salient to staff members (Bate & Robert, 2006). The touchpoints are then fed back to the EBCD project group (service users, carers and staff) at a co-design event, using edited films of user interviews. During the co-design event, small design groups are developed to collaboratively design quality improvement outcomes. A celebration event is held at the end of the process to allow those involved within the process to review the progress made.

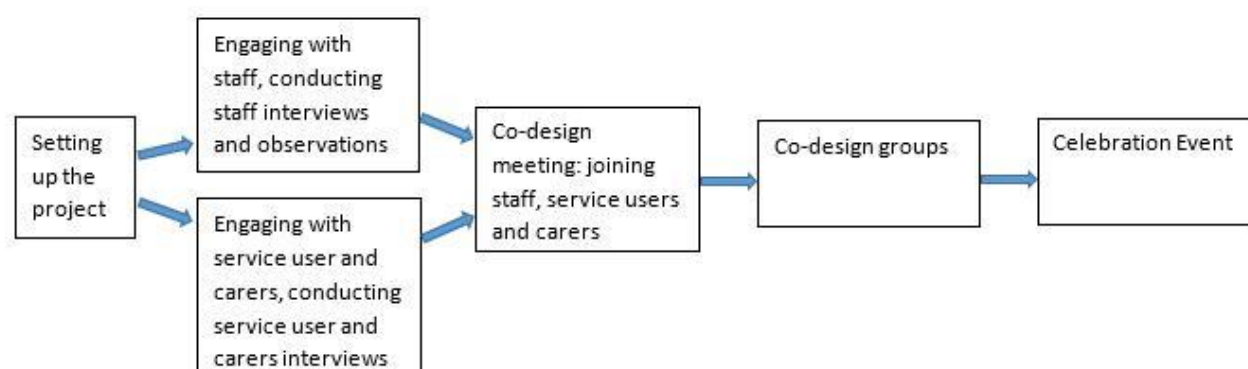


Figure 1: Diagram representing EBCD process based on Donetto and colleagues (2014).

Donetto et al. (2014) conducted a survey identifying the practices and developments made within EBCD from its conception in 2005. Fifty-nine projects had been completed internationally at the time of publication, with only 70% reported formally; many of which were not made public. Projects were conducted in a range of settings, such as cancer care services (Adams, Maben & Robert, 2013). Three projects have been completed within mental health settings (Cooper, Gillmore, & Hogg, 2016; Larkin et al., 2015; Springham & Robert, 2015).

There is inconsistent reporting of carer involvement within the EBCD literature. The Kings Fund (2013) protocol subsumes carers within the term ‘user’, which may be replicated in studies that have not named carer participation. One project has been completed to improve carer experiences (Ream et al., 2013), in a chemotherapy setting which resulted in the development of a carer DVD and leaflet. A feasibility study was completed with 43 carers, pre and post the project, and found carers had increased confidence in their supportive role and increased knowledge of chemotherapy (Tsianakas et al., 2015). This result suggests that EBCD can be used to improve carer experiences of services.

The available data suggested EBCD has successfully led to the implementation of small-scale improvements, for example, development of training manuals and tools and information packs (Donetto et al., 2014). Secondary benefits from the process, include: increased staff and user engagement within change activities (Donetto et al., 2014); positive challenges to attitudes held by staff and service users, with an increased understanding of each other’s perspectives and the development of a sense of community (Tsianakas et al., 2012); the promotion of mutual accountability between service users, carers, and staff (Boaz et al, 2016); and the facilitation of staff reconnecting to their personal values around care (Tollyfield, 2014).

The success of EBCD was reported to be dependent on a receptive environment for change, and the need for senior influences to ensure this. Co-design improvements needed to

be specific to the service involved, as difficulties were often met when improvements required other internal but separate teams to facilitate change (Tsianakas et al., 2012). Sustainability of the improvements made relied upon staff ownership of the outcomes. This was limited by high-turnover of staff in health care (Blackwell, Lowton, Robert, & Grudzen, 2017).

EBCD considerations for Mental Health.

A number of adaptations are required for effective implementation in mental health settings. Larkin et al. (2015) reflected on ethical considerations, including consent, anonymity, confidentiality, and data ownership. Due to the stigma surrounding mental health, care was taken to ensure that the legacy of the films was appropriately monitored. They highlighted the potential for re-traumatisation following the retelling or reliving their difficult experiences. They addressed this by ensuring safety procedures, such as providing service users with contact information for the named facilitators (Larkin et al., 2015). Springham and Robert (2015) acknowledged concerns around service users' personal life experiences being harnessed for the use of professional interests, and how staff members were not held to the same expectations as their service user colleagues (for example, not being asked to be filmed). The issue of power was raised by the authors, and appears to be a particular difficulty within mental health, where professionals can impact upon an individual's civil liberties (Springham & Robert, 2015).

Blackwell et al. (2017), suggested some difficulties could be addressed by using Dewing's (2008) principles of process consent for vulnerable people in research, which includes: having an understanding of someone's background and preparing them for their involvement; establishing capacity at baseline; gaining initial consent; monitoring and establishing consent throughout; and enabling mechanisms for gaining feedback and providing support.

Theoretical Factors within EBCD.

EBCD was developed from participatory action research, learning theory and narrative based approaches to change (Robert, 2013). It aimed to provide an environment that gives service users and carers a stronger voice. This stance challenges the current status quo, and requires service users, carers and staff to renegotiate their roles and reconfigure the balance of power held within the traditional structures in quality improvement work, and more broadly within the NHS (Donetto et al., 2014).

Allport's (1979) contact hypothesis may provide an explanation for how varied stakeholders can become united under certain conditions. He stipulated that: "equal status contact between majority and minority groups in the pursuit of common goals ... contact sanctioned by institutional supports ... leads to a perception of common interests and common humanity" p281, thus reducing the stigmatising attitudes held by each group. Corrigan and Shapiro's (2010) literature review of the impact of anti-stigma programs to address the discrimination associated with mental illness, suggested that contact had significantly greater impact on improving attitudes than protest and education (Corrigan, et al., 2001), and is maintained over time (Corrigan, et al., 2003). It is posited that EBCD offers a collaboratively established goal in a forum for sharing experiences from multiple perspectives to achieve its aim. The institutional backing required for these projects, supports the value of each member within the project.

Study rationale

Despite policy documents championing the involvement of service users and carers within quality improvement, there has been limited urgency in implementing this (Bate & Robert, 2006), despite a growth in EBCD projects in recent years. EBCD has been proposed as a means of translating qualitative data into action, resulting in meaningful, service specific

quality improvements, within a range of clinical areas (Cooper et al., 2016; Donetto et al., 2014). Further research is required to ensure reliable effectiveness and generalisability of the approach. This can only be facilitated by “understanding the social processes and mechanisms that produced the outcomes” p1. (Dixon-woods, et al., 2011). This is particularly apparent within the mental health context, where EBCD is still in its infancy. Whilst a ward-based EBCD project appeared to produce a dramatic reduction in complaints (Springham & Robert, 2015), EBCD as a methodology has not previously been applied within the complex context of improving family and carer involvement within a community mental health team (CMHT). The current study aimed to explore the perceived mechanisms that might facilitate the EBCD process with carers and family involvement, and to build a preliminary model of how an EBCD project works.

The following specific questions are addressed within the current study:

1. What, if anything, enables carers directly involved within an EBCD project to move from a position of non-engagement to engagement with a CMHT?
2. How do participants in an EBCD project perceive the project and their participation in it?
3. What factors do participants see as helping and hindering the EBCD project's progress?

Method

An NHS Research Ethics Committee reviewed and approved the research (Appendix B). All documents were reviewed by a service user group to ensure readability. Informed consent was gained from each participant, in line with BPS Code of Conduct (British Psychological Society, 2006). All identifying data were removed from transcripts to protect participant anonymity. Participants were made aware that one of the research supervisors was involved within the project. They were informed that this member of the research team would not read interview transcripts, and therefore their responses would remain confidential. To ensure this quotes included in the final report were anonymised and displayed in such a way as to prevent ready identification. As a participant observer the researcher would identify herself and explain her role at the start of every meeting to gain informed consent for data collection. If any member in the group did not wish to participate within the research, the researcher would not attend the session.

Context

The study was conducted within a CMHT in outer London. The trust had identified carer involvement as a key area for change within the organisation. The family and carer EBCD project was initiated in 2014, and was still ongoing in 2017. The project leader had been integral to the instigation of EBCD within the Trust, and had been involved in a previous successful project.

Design

The study adopted a grounded theory approach within a social constructionist framework (Charmaz, 2006). This research methodology was selected as it was developed to explore social action. EBCD is based on participatory action research, and relies upon the exploration of participants' experiences of their world (Charmaz, 2006). Grounded theory is a

methodology often used to approach areas of research that have not previously been explored (Corbin & Strauss, 2015). The current EBCD project with families and carers in a mental health context is the first of its kind. A social constructionist standpoint was selected as it acknowledges the researcher's own viewpoint within the interpretation of data (Charmaz, 2006). The author had a formal role within the EBCD project, however, this role was to document its work and theorise about its perceived processes and outcomes.

Participants

Participants were recruited from the existing EBCD project, using a stratified sampling approach. Whilst true representativeness was neither possible nor intended, the aim was to sample for sufficient diversity to capture as varied a range of perspectives as possible. The researcher included participants from all stakeholder groups. More staff members (N=12) than service users (N=2) and carers (N=2) were interviewed as there were a greater number of staff involved in the project and to include the different professions involved. The range of professions included psychology, occupational therapy, art therapy, family therapy, community psychiatric nursing and carer support. Years of higher education was collected for each participant, including any qualifications achieved in higher educational settings. See Table 1 for participant demographics.

Table 1: *Participant Demographic Information*

Participant	Age	Gender	Ethnicity	Years in higher education	
1: Staff 1	50-55	Male	White British	10	<i>Note:</i>
2: Staff 2	50-55	Male	White other	14	
3: Staff 3	55-60	Male	White Irish	10	
4: Staff 4	55-60	Female	White British	3	
5: Carer 1	60+	Female	White British		
6: Service user 1	35-40	Female	White British		
7: Service user 2	30-35	Female	White other	1	
8: Staff 5	40-45	Female	White Irish	14	
9: Staff 6	55-60	Female	Asian	4	
10: Staff 7	30-35	Male	Black British	8	
11: Carer 2	50-55	Female	White British		
12: Staff 8	45-50	Female	Black African	3	
13: Staff 9	55-60	Female	White British	6	
14: Staff 10	40-45	Female	White British	10	
15: Staff 11	60+	Female	White British	9	
16: Staff 12	45-50	Male	White British	7	

Pseudonyms have been used to ensure participant anonymity

Data collection and analysis

A semi-structured interview schedule (Appendix C) was developed by the researcher to address the research aims. Interviews lasted between 45-90 minutes and took place within the community team site. The use of open questions enabled the interviews to capture the richness of individuals' experiences and be responsive to participants' answers (Smith, 1995). Data collection and analysis ran concurrently. Additional questions were added to the schedule to explore emerging themes from the previous interviews, as is standard within grounded theory for theoretical development (Charmaz, 2006). Two of the original participants were asked to complete a follow up interview, one service user and one facilitator, to explore developments in the later stages of the project. These participants were chosen as they were part of the remaining EBCD team. The project was moved to a different team, therefore original

staff members could no longer be involved. In addition, the researcher attended a number of meetings throughout the EBCD process as a participant observer, engaging as a member of a co-design stream. Field notes were used in triangulation, in addition to the interview data. These were only drawn upon where they added something to the use of quotations from interviews.

Data analysis followed the method outlined by Charmaz (2006) and Urquhart (2013): initial coding, focused coding, and theoretical coding. Line-by-line coding of the verbatim transcripts was the chosen to enable the researcher to see actions within the data and stay “close to the data” p.51 (Charmaz, 2006). Line-by-line coding provided large quantities of data which were refined through focused coding, comparing between transcripts and between codes and data; also known as ‘constant comparison’ (Glaser and Strauss, 1967). The final phase of theoretical coding involved establishing the relationships between the emerging codes within focused coding, which facilitated theory development (Charmaz, 2006). The use of diagramming and memo writing facilitated the development of possible relationships between concepts and to support theoretical coding (Charmaz, 2006). The final theory was shared with the remaining EBCD team for respondent validation.

Quality assurance

To ensure the quality of the research, good practice guidelines were considered (Henwood & Pidgeon, 2003). Yardley (2000) specified the following characteristics: (1) sensitivity to context, including in this case participants’ perspectives and ethical issues; (2) approaching the topic with commitment and rigour; (3) transparency and coherence; (4) recognition of researcher impact on a theoretical and practical level.

Analysis was completed by the author, however, a sample of scripts were coded by an academic supervisor to assure reliability. Supervision, respondent validation and reflective

memos of category development and personal responses to the data were kept to enhance the methodological rigour of this approach (Strauss & Corbin, 2008), especially as the researcher had previously belonged to the service and might share some of the assumptions made by participants.

Reflexivity

The researcher was known within the CMHT, having worked alongside the team members during a nine month placement. This placement coincided with the instigation of the EBCD project. The researcher was present at the joint event as a staff member and was allocated to a co-design group that did not result in an outcome due to non-attendance of other staff members. Later involvement within the project was through invitation to co-design meetings, where the researcher participated within role plays and group discussions as a participant observer. The researcher was invited to meetings where the EBCD project was discussed with the wider team. The researcher's role as participant observer was known within the team, and group consent was gained at each meeting.

The researcher's relationship with the team may have influenced the project. Firstly, influencing staff engagement, by facilitating a friendly and comfortable environment for participation or limiting disclosure about the project. Secondly, the researcher may have been seen as part of the staff team by carers and service users, which may have impacted respondent's ability to be open in their interviews. It may have influenced the interpretation of the interviews and what was observed within meetings. To mitigate potential biases, data sourced from the researcher's observations were corroborated by the interview data and used in triangulation; the researcher's role was differentiated from her role as an active clinician in discussions with service users and carers; interviews were conducted after the researcher had left her post within the team; and a reflective diary was kept to reduce the researcher's interpretations being biased by her relationship with the team.

The researcher was attracted to the current project, due to an interest in service user and carer involvement. She was aware of the work completed within the Trust involving service users and viewed this favourably. She was mindful of the potential for service user and carer involvement to be tokenistic if not implemented in a meaningful way.

Results

A number of complaints by carers had been lodged against the CMHT prior to the project. Carer involvement had become a priority at Trust level, leading to willingness to try an EBCD project to improve carer involvement at team level. This followed an EBCD project that had been viewed as highly successful, which was a ward-based project involving staff, carers and service users. The project followed the EBCD process outlined by the Kings Fund (2013). Carers were recruited from a carer's group run in a charitable organisation in the community. Touchpoints were identified from filmed interviews with five carers, and were edited to create videos shown at the joint event. Four carers, three service users and twenty-two staff members attended this event. Four design streams were collaboratively generated from the touchpoints shown, and participants agreed to be part of each group. These included: psycho-education for carers, first meeting between service users and the team (with invitations to carers), confidentiality and service users' advanced directives (details of each group are displayed in Appendix D). Each group consisted of service users, carers and staff. Co-design groups met separately and discussed possible solutions. Two groups did not progress to developing solutions and two groups were merged due to non-attendance of staff to group meetings. Through the use of role plays and prototyping, a number of outcomes were established, namely, a training manual for staff delivered by carers and service users, a psycho-education group for carers, and an eco-mapping tool: paperwork aiming to elicit from service users who was in their social network and who they wanted to be involved in their care.

Throughout the project a number of organisational changes occurred. These included a service re-design, which resulted in staff's team membership changing, changes in location and management. Furthermore, the team underwent a care quality commission review, and had to address a number of areas of need. The process and the corresponding contextual changes are illustrated in Figure 2.

THE POSITION OF CARERS IN MENTAL HEALTH CARE: EXPLORING EXPERIENCE-BASED CO-DESIGN

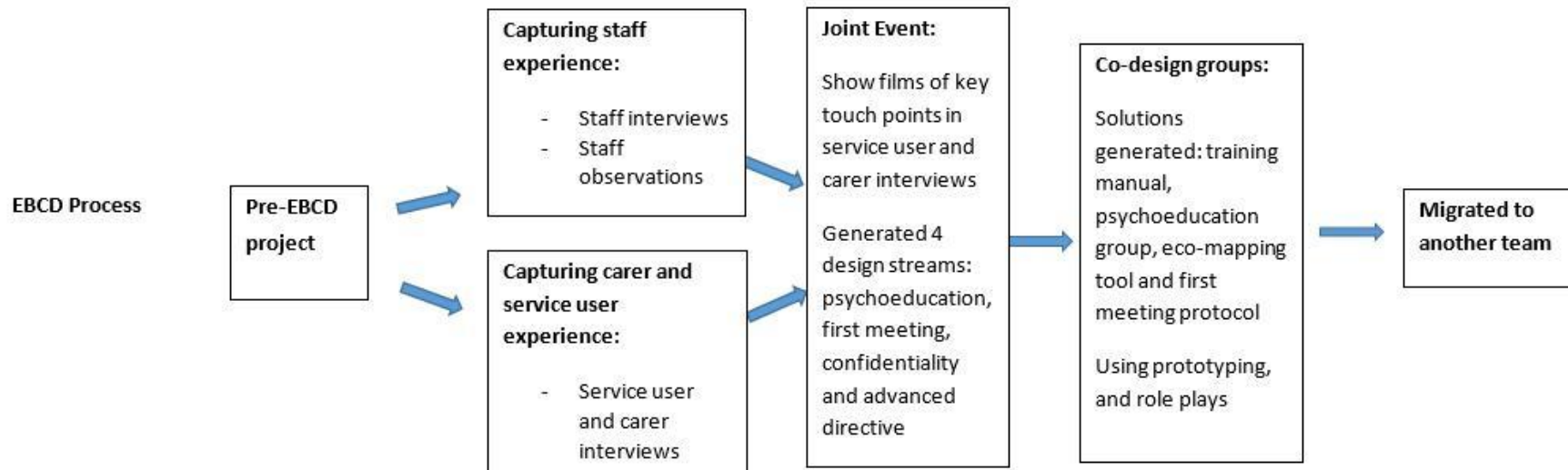


Figure 2: The contextual factors that took place during the EBCD project and at what stage within the project they occurred

A diagrammatic representation of the theory derived from the participants’ responses is presented in Figure 3. The figure depicts the main processes (categories) that seemed to be required for the successful implementation of the project with families and carers, in addition to the sub-categories that appeared to impact implementation. This section outlines each category, with the corresponding sub-categories. Evidence of the coding process can be found in the appendix (E, F, G). Field notes did not contradict interview data in any significant way and were only drawn upon to add to the use of quotations from interviews. This figure was distilled from an original theoretical diagram displayed in Appendix H.

Planets aligning

Table 2:

List of categories and sub-categories from focused coding

Planets Align	Prior success
	Fits with organisational and personal values
	Multiple stakeholder commitment

Many of the participants reflected upon factors that would be required for the implementation and continued development of EBCD. Due to the complexity of these factors, the implementation of EBCD was described as the *planets aligning*. Firstly, EBCD was reported to have developed a reputation within the Trust for addressing areas of difficulty with success, *prestige of EBCD*. It was recognised as an ‘agent for change’ (Staff 5) that could be used to address this problem.

“I guess there was a big project early on in the history of [trust-based service user network][...] which was around an inpatient unit. So I saw the... from supervising [facilitator] I kind of got a sense of where that project was at and what it ended up achieving ... provided very compelling evidence that the methodology of EBCD can be a really good change you know, agent for change”. (Staff 12)

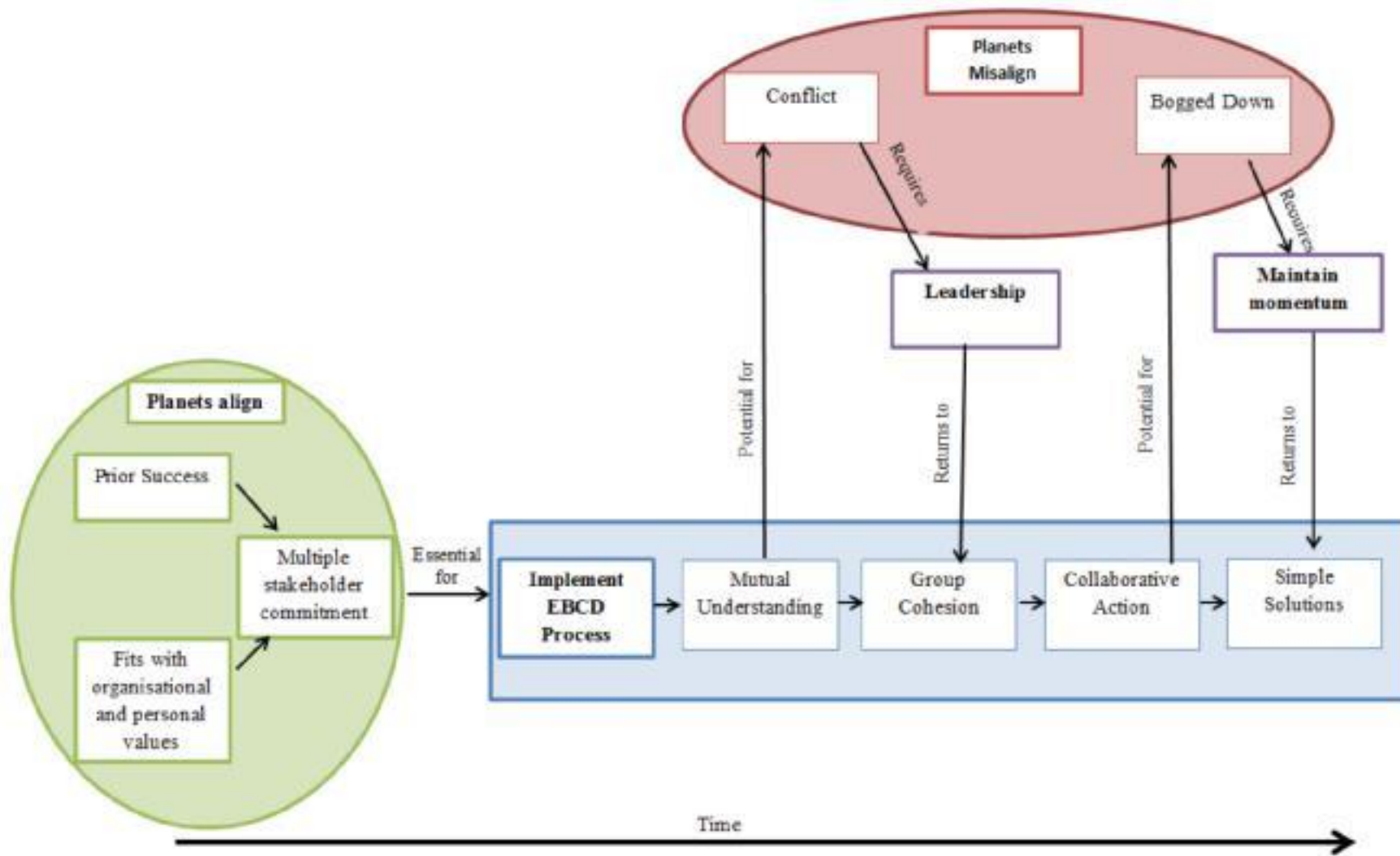


Figure 3: Diagrammatic representation of the preliminary theory

Respondents reported that EBCD had to *fit with organisational and personal values* in order for it to be supported by the organisation and to motivate individuals' to engage within the process. These motivational factors included, at the organisational level:

A recognition of the need for service user and carer involvement, as supported by local and national policies.

“[Senior staff member] was charged with, of bringing, of developing a new carers' strategy that had just run out. [...] so all the planets aligned and at the top level. Complaints, must do's, carers expressing huge amounts of anger. So there was a massive need” (Staff 1)

At the personal level:

A personal hope for change. Many participants drew on their personal experiences of service user and carer involvement to describe their motivations for engaging within the project. Involvement was valued as a common sense approach to changing services for the better, recognising that imposing change may not result in beneficial change.

“If I come up with a good idea, and I think, oh this is what they should use but ultimately the people who use it are the staff and the service users aren't able to invest in it then it will fail, whatever, however, good the idea may be. So I always try to involve everyone with that set of things”. (Staff 7)

Staff members interviewed focused on the idea that service user and carer involvement was compatible with their daily practice and ways of working.

“I've come to learn to work with individuals but also had a systemic view [...] so when [facilitator] told me about this I thought this is what I do all the time, and this is now applied to the conversation of change, so my bread and butter therapeutically is to bring about change by enquiring, by working with the system therapeutically.” (Staff 2)

Finally, it was acknowledged that for a project to be implemented all stakeholders needed to be invested in the project; *multiple stakeholders commitment*.

“The Trust had kind of put their hands up and said, we’ve made mistakes. And we want to see if we can change. And I think they realised, I was hoping that, [...] that by involving carers in this project, that they would get an insight into what our lives are actually like. [...] so I kind of jumped at it in the end, once I’d thought about it. Thinking change is good and change is needed, [...], I was hoping that it would bring together everybody within the Trust service, whether it was commissioners, service users, counsellors, nurses, whoever it was, for us all to be on an even level. And to try to talk things through and yeah I was interested then to see where it was going to go” (Carer 2)

Implement EBCD process

Table 3:

List of categories and sub-categories from focused coding

Implement EBCD Process	Mutual Understanding
	Group Cohesion
	Collaborative Action
	Simple Solutions

Participants reported a number of key elements within the EBCD process. They stated that showing the carer and service user videos and providing space to share experiences was one of the more memorable elements of the EBCD process. Participants reported these narratives enabled staff to recognise that there were problems in current practice and that there was a need for change. One participant stated that “imposed change is resisted change”, so for a helpful outcome it was essential for all stakeholders to acknowledge the problem. The narratives were described as helping staff to reconnect with the human elements of their work

and their ideals for working in mental health, which were suggested to be lost within routinised and tick box tasks.

“The videos that are being shown are the individuals saying this is how I feel, this is how it felt, this is how I was looked after, this is what I think could have gone well. [...] I guess it tugs at people’s heart strings for want of a better word. And you could see that happening, you could see people’s enthusiasm and eagerness to change, develop within that room. You could see people thinking about what can we do differently.” (Staff 7)

Participants reported that hearing others’ perspectives enabled them to place themselves more readily in another’s position. The various group events within the EBCD process facilitated a space for the development of *Mutual Understanding*. The development of this shared understanding is posited to reintroduce a human element into the process and contributed to the lessening of the divide between service users, carers and staff.

“I am much more, understanding about what situation faced by clinicians after that training. Because previously I could only see things from my point of view, and thought “how could they not be so unsympathetic to my situation?” but obviously they didn’t know what went on before my [relative] had the breakdown” (Staff 6)

It was proposed that there is a process of “airing what needs to be said’ (Staff 10), before the co-design group could move forward into a state of *group cohesion*. All stakeholders within the group were given the opportunity to voice their opinions and experiences. The diversity of perspectives was respected and positively valued.

“I think once we moved on from that initial stage where everyone is airing what they needed to air and started talking about plans going forward, I thought there was space

to talk, I hope, and I found it really helpful to have such a range of people in the room, who had ideas, lots of ideas.” (Staff 10)

Following the formation of a cohesive group, stakeholders were then able to focus on collaboratively developing solutions for the problems that had been highlighted; *collaborative action*. The lessening of the ‘them and us’ divide enabled multiple perspectives to develop ideas for action, and staff membership ensured that these solutions were realistic for clinical practice.

“We can all agree, we can disagree, we can all come at something from a different perspective. But before the day is out, we have all agreed what is going forward. So it’s not been anyone person saying ‘oh actually, we’re going to be doing this’” (Service user 2)

There were a number of outcomes of the project at this stage, namely the development of an engagement tool, a psycho-education group, and a training manual that would be rolled out by carers and service users involved within the project across the Trust. It is proposed that for solutions to be sustainable they needed to be simple and fit within clinical practice.

“Of course what we come out with is obvious and simple, but it’s not being done, so there’s something not obvious about that.” (Staff 1)

In addition to practical solutions, there were secondary benefits. These included service user and carer empowerment, personal skill development and a firmer belief within the Trust about the value of user involvement in design and development. Generating solutions further supported stakeholders to understand the multiple perspectives within the group, and there was an acknowledgement that carers’ wants were reasonable and could often be solved by simple solutions; they often expressed a focus on relational elements. Carers were also more able to recognise the time restraints and pressures placed on staff in these settings.

“My hunch is that some are feeling empowered, some feel that finally we are involved, we are not just talking, we are actually doing it. So it’s an experienced change. So I think that makes a big difference. Seeing something is being taken seriously”. (Staff 2)

Maintain Momentum

Table 4:

List of categories and sub-categories from focused coding

Maintain Momentum	Communication
	Showcase outcomes
	Benefits for all

Many participants reported that EBCD was a long process. The project started in 2014 and was not completed by the time of this report. Participants noted that the momentum within the project ebbed and flowed, and suggested means of *maintaining momentum* to “keep the project alive” (Staff 12). These included:

(1) Increasing *communication* amongst stakeholders, as it was felt that changes happened within the project and those not directly involved were not informed, which inadvertently limits co-creation, and providing opportunities to *showcase outcomes* of the work at conferences to gain acknowledgement for efforts outside of the project and an appreciation of what has been achieved;

“Yeah I think, everybody doesn’t know where this is at and where this is going, so it’s sometimes you know, important to remind people to update people, refocus, [...] keeping an awareness going. Otherwise it’s a marginal project” (Staff 3)

“We presented some of our work. At that point we hadn’t quite got to the final product if you like or where the streams were going, but after it all ... some other staff members from the trust, came up and said this sounds amazing. And they said it in front of the families and carers and for the first time, they felt like they were really doing something,

and they were all so pleased and really buzzing to be involved. It was really nice to see”. (Service User 2)

(2) Presenting the project as providing *benefit for all* stakeholders, by highlighting the outcomes as “not doing more, but doing differently” (Staff 9) and how outcomes could make future work easier;

“The methodology [...] it enables us to see that this is kind of, it’s not an added extra, it should be integral, it’s fundamental rather than this, “I’ve got to do a carer’s assessment and I’ve got to do that” (Staff 12)

Leadership

Table 5:

List of categories and sub-categories from focused coding

Leadership	Senior and local leadership
	Project facilitation

Leadership was an important factor within the EBCD process. Leadership was conceptualized by senior and local management, as well as, from the project facilitators and peer workers in the project. Senior and local leadership was raised within the interviews as a must for supporting staff to be fully engaged with the project; for sustaining solutions in the future; and providing the project credibility.

“So I think I've learned that if the managers don't engage there's no way round that” (Staff 1, Interview 2)

“For clinicians, [...], there was a recognition that this was taken seriously, [...]. And for service users and carers [...] they felt they were taken seriously. That really this is something the whole trust, with its hierarchy and authority, really want this to happen”. (Staff 2)

Project facilitators were instrumental in the smooth running of the EBCD project. The participants reported that they adopted a responsive approach and were able to recognise and act upon barriers and seek people who could address them.

“We want to be responsive and work with whatever comes up. Because it’s not just the solutions that are emerging and coming up, it’s also the blockages, the barriers that are coming up and to deal with that takes time and space”. (Staff 2)

Facilitators were important in moving the project forward when the groups were striving for cohesion. Participants stated that the process of ‘airing what needs to be said’ became circular and could result in no collaborative action. Facilitators were required to acknowledge the past experiences, and drive the group forward by reminding participants “Everybody is working to the same ends” (Carer 1).

“I’m often quite surprised by how much of a therapist part of myself that I have to use in that, as a kind of peace negotiator, but as a way of keeping the problem going, both for staff and service users, especially when both sides go into attack mode and don’t want to come together because they are feeling injured”. (Staff 1)

Furthermore the facilitator was needed to support the movement from inaction to action within the project, by sifting through group ideas to fix a plan for action. This approach may have limited the co-production, where ideas were formed by the group; however, actions were collaboratively sanctioned.

“I think, just having [facilitator] there made it possible to sit down and write some stuff down and start to plan, sessions and the content and what need to be in them. And I think that was really important”. (Staff 10)

Facilitators tailored the direction of the project, focusing on outcomes that could be resolved quickly. This approach was taken to maintain motivation and engagement within the project.

“Why would you go for the longest projects and hardest projects first, when [...] it’s a quicker process for the other two, so let’s get those two done and dusted, get them working? And then revisit the ones that are going to be a much longer process. [...] Much more about policy and HR and the rest of it, and how it all works and the structure” (Service user 2)

Planets Misalign

Table 6:

List of categories and sub-categories from focused coding

Conflict	Staff feeling ‘attacked’
	Legacy of service user and carer involvement
	All stakeholders feeling unsupported
Bogged down	Major organisational change
	Lack of experience in design
	Unfeasible outcome
	Insufficient resources
	Resistance change

Participants’ responses highlighted factors which described when the *planets misalign*. These were arranged into two categories: *Conflict* and *Bogged down*. Many participants acknowledged initial *conflict* within the co-design groups, with one participant suggesting it was the meeting of “two warring factions” (Staff 1). Participants reported that sessions were initially used by carers to share further difficult experiences within the Trust, leaving *staff feeling ‘attacked’*. There was an acknowledgement of the need for these stories to be heard to identify potential solutions, but this became overwhelming for some staff who felt they were committed to change and family involvement.

“Most of it came from the families and carers, they were very fearful of saying anything. Or they would go to the complete opposite and criticise, you would find that the meeting would turn less about co-production and more about some way to, as a space to kick the service as the staff were sat there, which must have been awful for them to hear”
(Service user 2)

Service users and carers reported that they felt that they were respected and heard within the group, which suggested that there was an acknowledgement of their expertise by experience. However, carers reported their concerns about power, particularly stating that the group cohesion was terminated at the end of each session, which may reflect the *legacy of carer and service user involvement*. Carers reported a history of being left out and disempowered by services.

“As equal as they wanted it to be, and they respected that, and they were, we were all trying to be very equal within the room and that to some extent does work. But you are very aware that the minute you leave that room, they will go back into their role and they will go back into their job that they are doing, and you don’t know what they are going to say to your care co-ordinator”. (Carer 2)

There was an expressed need for further support for all stakeholders at points of emotional intensity. Accessing carers from an existing external carer’s group was meant to address this by providing a supportive forum; however, this appears not to have been sufficient. This is different from the situation with service users, who were provided a support group through their membership of a trust run group.

“The carers, we don’t have debriefing, we don’t have colleagues that we can turn to and say, could we just run over this with me or I felt like this. It was kind of like, at the end of the meetings [...] you know, really we had nothing”. (Carer 2)

“It’s really important, obviously not to be defensive in any way. [...] that might be easier for some members of staff than others, and it may be something people need a bit of support with”. (Staff 10)

These difficulties were diffused by leadership within the project. Project facilitators were able to notice blockages and address them, and smooth over conflicts between separate groups. Leadership was enacted by both professional staff and peer workers in the current project.

Participants described a number of themes that contributed to the project becoming *bogged down*. Firstly, the project was implemented during a period of *major organisational change*, in which the host team was divided into two separate teams, alongside a change in manager and site. This is often the reality of ‘designing in the real world’ (memo following conversation with facilitator).

“It was a big change, they were trying to get their heads around that, [...], it possibly didn’t create the right circumstances to enable people to get involved in this.” (Staff 12)

This change seemed to impact staff morale and engagement within the project.

"There have been an awful lot of ‘prioritise for discussion’ in team meetings, just in surviving. [...] if it’s happening around the time you’ve got enormous change and challenge for a team, it’s inevitable that some people just can’t prioritise it. That their heads are in other places.” (Staff 10)

Although numerous outcomes were identified, a number of factors complicated the development of solutions. For example, one work stream within the co-design project folded, and it is proposed that this was due to the task being seen as *unfeasible* and relying upon wider

structures within the Trust to implement change. Other potential solutions were limited by *insufficient resources* and reflected a need for a greater backing from the Trust.

“They are quite a tricky area, in terms of confidentiality and advanced agreements, it’s like, well where do you begin to tackle this”. (Service user 2)

It was proposed that the groups became stuck at the point of action. One participant stated that it is ‘counterintuitive’ (Staff 12) for stakeholders to work with prototypes and discard unhelpful solutions. Therefore, it was felt that the *lack of design experience*, hindered the development of solutions. This may be a product of anxiety; flexibility in thought and perceived agency for a solution is required and may not fit with the norm of service design within the NHS.

“There’s the actual doing, the actual, “Okay, so this is the issue, we’ve heard all these different voices now what are we going to do about it?” And my sense was that just, that was really where it started to get bogged down”. (Staff 12)

Many participants reflected on the *resistance to change* during the project. A number of ideas were raised to explain this, including, prioritising demands placed on staff time; a lack of belief in the need for change; and the perception that often staff were ‘volunteered’ to participate as opposed to volunteering to participate. Each of these factors could result in a disengagement from the project and a need to move the project to an environment that had the space and support to engage.

“Sometimes it’s easier to go along the way you have been doing than to do any change [...]. That’s what I think is difficult about the whole of the project”. (Carer 1)

“So we’ve taken the project away from the community teams and we’re piloting it on the wards. [...] Maybe we’re doing that because the planets align there, because the management is engaged through that”. (Staff 1, Interview 2)

These difficulties prompted efforts to maintain momentum, through increasing communication, promoting the benefits for all, and highlighting the progress that had been made within the project.

Discussion

The results of the study are represented in a preliminary theory of the processes involved in an EBCD project with families and carers. The theory indicates that certain conditions needed to be met prior to the initiation of the project, namely commitment from multiple stakeholders, which was facilitated by the approach being consistent with organisational and personal values and previous successes using the approach. This process has been recognised in previous EBCD projects (Larkin et al., 2015). Once these conditions were met, a joint event facilitated sharing personal experiences and perspectives enabling the development of a mutual understanding around the aim of the project and to affirm commitment to the cause. These stories were emotionally charged and appeared to help staff to reconnect to their personal values and take on board another's perspective.

Following the development of a mutual understanding, stakeholders needed to come together to form a co-design group. At this stage there was a process of bringing together diverse groups, with different perspectives and expectations. Allport (1979) suggested certain conditions need to be present for the reduction of stigma. These included each member having equal status, in the pursuit of a goal that fostered common interests and was supported by institutional supports. The EBCD process appeared to facilitate these conditions, and enabled the multiple stakeholders to form a cohesive group. However, there was a need for differences to be shared and acknowledged. This has been described in other EBCD projects, where groups showed an increased understanding of the 'other' perspective, and created a shared identity (Tsianakas, et al., 2012). All groups needed to invest in the joint aim and be seen on a level footing. This process is also consistent with Haslam's (2014) suggestions for the application of social identity theory and social categorisation theory to healthcare contexts. In particular, Haslam (2014) suggested that people's sense of group belonging can have powerful effects, and that working with people's identities can make things happen (Holttum, 2014). Other

authors have suggested that EBCD provides a space to value service user and carer knowledge and elevate them from their traditional positions of passive recipient of care (Bate & Robert, 2007). This is shown within the current EBCD project, as all stakeholders were respected for their expertise and knowledge. This may require particular skills in a facilitator. This project was not immune to the power imbalances reported in other projects (Larkin et al., 2015).

Tuckman (1965) outlined a staged approach to group development which could be used to explain the progress made within the EBCD group. His staged model encompassed four stages: 1) *Forming*, orientating the group around the task; 2) *Storming*, the group responds to conflict within the task; 3) *Norming*, a cohesive group is formed, opening up the freedom for personal opinion; and 4) *Performing*, the group works together challenging its energies into the task. In relation to the current EBCD process, the sharing of experiences may have facilitated the formation of the group and highlighted the importance of the task and joint goal. However, some conflict was experienced in relation to “airing what needed to said” (Staff 10), where staff felt “attacked” and service users and carers felt that there was a repetition of previously unhelpful means of involvement. Support is required at this point for all stakeholders, and should be offered in a concrete form by project facilitators and local management. Two groups were able to move beyond this position and described the openness and value of multiple perspectives to develop solutions; and reached a position of performing.

Another important stage within the emerging theory is that of collaborative action. At this stage the multiple perspectives are used to create simple, sustainable solutions which can be readily implemented within clinical practice. In the current project, groups found it difficult to move to a point of action and had to be supported into action by the group facilitator. This may limit co-production, however, if the actions were based on group ideas this remains closely aligned to co-design. The authors of EBCD stated that ‘users’ were co-partners not co-leaders (Bates & Robert, 2006), and so some leadership is necessary within the project. At times the

group's mandate can be too large for the scope of the project and therefore perceived as unfeasible. Perceiving the product to be unfeasible and out of their direct control can lead to disengagement from the project. This was similar to difficulties that arose in an EBCD project where solutions relied upon external services (Tsianakas et al., 2012). This suggests that future projects should focus on simple solutions that can provide quick outcomes and maintain motivation for those involved. Staff can feel less burdened in the acknowledgement that these small but significant factors can be readily implemented (Blackwell et al., 2017). As found in the literature, participants of the current project reported secondary outcomes, namely service user and carer empowerment and a staff re-connection with their values (Cooper et al., 2015).

The current project highlighted the factors that can lead projects to becoming inactive. This project was carried out at a time of major organisational change, which appeared to impact the staff morale but also changed the structure of their team. There was a loss of local management, which led to there being reduced support or commitment to the project at that level. This is consistent with process research by Leamy et al. (2014) on implementing change in the NHS. Resistance was met to change, due to the positioning of the project as an additional burden or task or a lack of acknowledgement that there was a problem. This has been found in other studies using EBCD within physical health settings (Bate & Robert, 2007). The theory suggested key factors that could maintain motivation within future projects, if faced with similar difficulties, included communication, promotion of the benefits, and showcasing outcomes.

Leadership was reported to be fundamental to the successful implementation of the EBCD process, both from project facilitators but also senior and local management. Future projects need responsive leadership, facilitating a space for creative and innovative ideas through collaborative action, and focusing on efforts to maintain momentum, energising members to sustain their efforts towards meeting the end goal. This style of leadership fits

within Bass's (1990) transformational leadership model. EBCD can be a lengthy process, faced with the complexity of change within the NHS. The facilitator of the current project appeared to be able to reduce the complexity, by focusing on simple solutions and presenting the goals and outcomes clearly, whilst identifying obstacles. Their main role was perhaps holding hope for the group in times of uncertainty (NHS Leadership Academy, 2013), which was enacted through addressing the obstacles, and providing support for to all stakeholders. However, the project facilitator could not lead the project without the support of senior and local management, which provided the project with credibility and resources for implementation. Project facilitators, and in the current project peer workers, can address conflict within co-design groups in order to establish productive collaborative action.

Limitations to the research

The researcher conducting the study maintained a role as participant observer within the project. Although, data accumulated were used to triangulate the interview data, it may have limited the findings and influenced the interpretation of the data. Due to the researchers' role within the team, participants were known to the researcher in a clinical role, which may have enhanced or limited their responses at interview. These factors were mitigated by researcher reflectivity, independent audit, and respondent validation of the theory. Field observations did not contradict the interview data in any significant ways. Furthermore, the external supervisor was significantly involved within the project; measures were taken to limit this influence on the data. For example, they were not involved in data analysis. Quotes included in the final report were anonymised and displayed in such a way as to prevent ready identification.

It was recognised that participants would know each-other, and may recognise each other within the data. However, the interview questions were not tailored to explore personally sensitive data, and it was believed that it was unlikely that unknown information would be

revealed within interviews or the quotes. Only quotes relevant to the developing theory were included in the report and were selected sensitively.

Attempts were made to ensure diversity in perspectives that were heard, though it is possible that some key stakeholders were missed. For example, those voices that were not involved within the project but still part of the staff team or service user and carer population served by the team. The study was able to capture a range of perspectives and to illustrate both positive and negative perceptions of the project's progress and processes. Potentially the illustration of both challenges and successes may help others in future EBCD projects of this type.

The project had not reached completion at the time of the report. Therefore, processes that occur toward the end may not be captured within the current theory. The current project was conducted at a time of instability within the team, and may have caused staff anxiety. Therefore, this theory may be more helpful in relation to some of the difficulties that arise at a time of instability and be less transferable to EBCD projects conducted under more stable circumstances.

Considerations for clinical practice

Limited research explored the processes that facilitate the implementation of EBCD, especially in mental health. Therefore, the theory produced from the data collected within this research will support future projects to achieve their potential, by highlighting key processes involved for consideration.

Clinical psychologists would play a helpful role in the implementation of future projects. The Division of Clinical Psychology (2010) has developed a framework outlining the role of clinical psychologists as leaders. The framework highlights clinical psychologists' skills in engagement and collaboration, which appeared to be important components within the

current EBCD project. The project facilitator needed to bring in multiple stakeholders, hold onto the vision of the project, whilst supporting collaborative action. Furthermore, clinical psychologists have an understanding of group dynamics that can be utilized to support the formation and collaboration of the group. Finally, Clinical psychologists' role is to alleviate distress and promote psychological wellbeing (British Psychological Society, 2008). This focus would help to ensure stakeholders were supported throughout the process.

Future research

The proposed theory is preliminary. Further research needs to test its validity. Future research should examine an EBCD project with this number of stakeholders in a more stable context, to shed further light on the impact of organisational disruption on the effectiveness of EBCD. As a form of organisational change agent, the model of EBCD presented here may have applications for other kinds of change projects. The issue of outsourced support groups for carers or service users is something that could be investigated, as such groups do not have a specific focus on co-design work in which some members may be engaged. Furthermore, complex projects involving a large number of stakeholders in scattered parts of large NHS trusts may be particularly difficult in relation to maintaining lines of communication, and it may require research into innovating ways of tackling this. Finally, research could examine different ways of inducting all stakeholder groups and staff at different organisational levels into the work of EBCD so that they do not unwittingly undermine it or have expectations that cannot be met.

Conclusion

This study presents a preliminary theory of the processes involved in an EBCD project with families and carers. For a project to be successfully implemented efforts need to be made in setting up the project, ensuring that the project fits with organisational and personal values of the institution and attains multiple stakeholder commitment. A mutual understanding of the problem needs to be acquired, supporting the diverse groups to collaborate with a joint aim. This process can be supported by leadership. Project facilitators need to be responsive to the relational elements throughout the process and provide support to all stakeholders. Projects cannot be sustained if there is not sufficient local leadership; if project aims are perceived as unfeasible; and if the solutions are not simple and readily integrated into clinical practice. EBCD projects can be lengthy, and require motivation to be sustained throughout the project, through communication and showcasing outcomes. Further research is required to assess the validity of the theory presented and to ascertain any difference that arises when conducting a project in a more stable context.

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Appendix A – This has been removed from the electronic copy

Appendix A – Ethics documentation

Some items have been removed from the electronic copy

Staff Information sheet

Information about the research

Hello. My name is Laura Chisholm and I am a trainee clinical psychologist at Canterbury Christ Church University. I would like to invite you to take part in a research study. Before you decide it is important that you understand why the research is being done and what it would involve for you.

Please take your time in making your decision and talk to others about the study if you wish. Part 1 tells you the purpose of this study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study.

What is the purpose of the study?

The current study aims to explore people's experiences of taking part in the Social Network experience-based co-design project running at the Erith Centre, in the hopes of determining the factors that contribute to or hinder the effectiveness of this service development strategy.

Why have I been invited?

I am hoping to speak with people that have been involved within the experience based co-design project at Erith Centre, and would really appreciate hearing from a range of perspectives. All members of the experience based co-design will be approached to participate in the study.

Do I have to take part?

Participating within the project is voluntary, so it is up to you to decide whether to join the study.

If you agree to take part, I will then ask you to sign a consent form. You are free to withdraw from the study at any time, without giving a reason.

What will it involve if I take part?

Taking part in the study will involve two interviews held on two separate occasions. The first interview will last 1 hour, organised at a time that suits you in January 2016. Within this discussion, I will ask you a few questions about your experience of taking part in the experience based co-design. The second interview will last 30 minutes, again at a time that suits you in April 2016, talking about how the project has developed. The interviews will take place at the Erith Centre.

The interviews will be recorded on an audio recorder, and transcribed for data analysis.

Your experiences of the project will be read by myself and my supervisors Dr. Sue Holttum and Neil Springham. Any personal information will be kept confidential. The audio files and transcribed accounts will be stored on a password protected memory stick and then stored on a password protected computer.

Should you require any support following the interviews, please use the contact details outlined at the end of this sheet.

Expenses and payments

To try to minimise the inconvenience of participating within the study, your travel to and from the Bexley Recovery Team will be paid for.

What are the possible disadvantages and risks of taking part

Some people can find it difficult to speak freely about their experiences, especially to someone that they do not know. Attempts will be made to make you feel at ease within the interviews. If you should feel uncomfortable at any point within the discussions it is important to raise this and the session can be stopped.

What are the possible benefits of taking part?

We cannot promise the study will help you personally but we hope that the information that we get from this study will help to improve the efficiency of future experience based co-design projects and in turn help those who use services and professionals to work jointly to further improve NHS services.

What if there is a problem?

If there are any complaints about the way the study has been run or how you have been treated during the study, this will be addressed. The detailed information on this is given in Part 2.

Will my taking part in the study be kept confidential?

Yes. Ethical and legal guidelines will be followed to ensure that all information about you will be handled in confidence. The details are included in Part 2.

This completes part 1.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2

What will happen if I don't want to carry on with the study?

If you decide that you no longer wished to be part of the study, you have the right to withdraw at any point. This can be after signing the consent forms or even after participating in the interviews. To do so, you would need to contact me using the contact details listed at the bottom of this sheet.

If you have already participated in one or both of the interviews, we would like to use the data collected up to the point of your withdrawal.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to me and I will do my best to answer your questions. If you remain unhappy and wish to complain formally, you can do this by following the NHS Complaints Procedure. Details can be obtained from the Oxleas NHS Foundation Trust website. Alternatively you may contact Professor Paul Camic, Research Director, Salomons Centre for Applied Psychology, Canterbury Christ Church University – paul.camic@canterbury.ac.uk.

Will my taking part in this study be kept confidential?

Names and contact details for those participating within the Social Network experience based co-design project have been retrieved from those facilitating the project, and will be used solely for recruitment purposes. This information, alongside the information which is collected from you during the course of the research will be kept strictly confidential. The conversations will be audio recorded and transcribed for data analysis. These files will be stored on a password protected USB stick and on a password protected computer. Only those involved within the data collection and analysis will have access to this information. When the audio material is typed up, names of people and places will be changed to protect anonymity of participants. The audio files will be erased after being typed up. The written transcripts will be kept for 10 years before being disposed of securely. The results of the study will be collated into a report, and individual quotes may be taken from interviews, however, these quotations will be anonymised.

Limits to confidentiality

The only situation in which I would pass on information to a third party would be if you said something during our conversation that led me to believe that you or someone else may be at risk of harm.

What will happen to the results of the research study?

It is hoped that the findings from the current study will be published within a reputable journal. Access to this report will be provided to those that participate within the study, if requested by the participant.

Who is organising and funding the research?

This research is being organised and funded by Canterbury Christ Church University.

Who has reviewed the study?

All research projects completed by trainees at Canterbury Christ Church University are looked at and approved by a review panel at the Salomons Centre for Applied Psychology, Canterbury Christ Church University. As this project is running within the NHS, it has also been looked at by an independent group of people called a Research Ethics Committee. This committee is designed to protect your interests.

This study has been reviewed and given favourable opinion by _____ Research Ethics Committee.

For further information, please see contact details below

- Specific information about this research project.

If you would like to speak to me and find out more about the study or have questions about it answered, you can email me at laura.chisholm@nhs.net and I will arrange a time to discuss your queries in more detail. Alternatively, you can contact the 24-hour voicemail service on 0330117070 and I will return all calls. To ensure that the message reaches me, state my name: Laura Chisholm and provide your name and telephone number.

To understand more about experience based co-design, please see the following website: www.kingsfund.org.uk

- Advice as to whether they should participate.

Deciding whether to take part in research can take time and often talking this through with someone else can be really helpful. It might be helpful to speak with other members of the experience based co-design project or the team facilitating the EBCD project.

You can also contact me at laura.chisholm@nhs.net and I will arrange a time to speak with you about the project further.

- If you are unhappy with the study.

If you feel unhappy with the study and would like to speak to me, you can leave a message for me on a 24-hour voicemail phone line at **01892 507673**. Please say that the message is for me, Laura Chisholm, and leave a contact number so that I can get back to you.

You can also email me at laura.chisholm@nhs.net

However, should you wish to speak to someone other than myself, please email Neil Springham at neil.spingham@oxleas.nhs.uk or Professor Paul Camic, Research Director, Salomons Centre for Applied Psychology, Canterbury Christ Church University – paul.camic@canterbury.ac.uk.

There is also an online complaints form, which you can access following the link below: <http://www.oxleas.nhs.uk/compliments-and-complaints/>

The Support, Empowerment, Advocate, Promote (SEAP) team can provide you with support in completing this form should you need it. They can be contacted by telephone on **0330 440 9000**.

The Bexley Advocacy for NHS Complaints team can also provide further support with registering a complaint and can be contacted by email info@advocacyforall.org.uk and telephone: **020 8300 9666**

Information about the research

Hello. My name is Laura Chisholm and I am a trainee clinical psychologist at Canterbury Christ Church University. I would like to invite you to take part in a research study. Before you decide it is important that you understand why the research is being done and what it would involve for you.

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Why have I been invited?

I am hoping to speak with people that have been involved within the experience based co-design project at the Erith Centre, and would really appreciate hearing from a range of perspectives. All members of the experience based co-design will be approached to participate in the study.

Do I have to take part?

Participating within the project is voluntary, so it is up to you to decide whether to join the study.

If you agree to take part, I will then ask you to sign a consent form. You are free to withdraw from the study at any time, without giving a reason.

What will it involve if I take part?

Taking part in the study will involve two conversations held on two separate occasions. The first discussion will last 1 hour, organised at a time that suits you in January 2016. Within this discussion, I will ask you a few questions about your experience of taking part in the experience based co-design. The second discussion will last 30 minutes, again at a time that suits you in April 2016, talking about how the project has developed. The conversations will take place at the Erith Centre.

The conversations will be recorded on an audio recorder, and transcribed for data analysis. Your experiences of the project will be read by myself and my supervisors Dr. Sue Holttum and Neil Springham. Any personal information will be kept confidential. The audio files and transcribed accounts will be stored on a password protected memory stick and then stored on a password protected computer.

These conversations can often draw on difficult memories and emotions, and support will be provided should this occur. Should you require support following the conversations, please use the contact details outlined at the end of this sheet.

Expenses and payments

To try to minimise the inconvenience of participating within the study, your travel to and from the Bexley Recovery Team will be paid for.

What are the possible disadvantages and risks of taking part

Some people can find it difficult to speak freely about their experiences, especially to someone that they do not know. However, I hope you will have met me at one of the meetings before we have the first conversation. I will also try to make you feel at ease within the conversations. If you should feel uncomfortable at any point within the discussions it is important to raise this and the session can be interrupted or stopped.

What are the possible benefits of taking part?

We cannot promise the study will help you personally but we hope that the information that we get from this study will help to improve the efficiency of future experience based co-design projects and in turn help those who use services and professionals to work jointly to further improve NHS services.

Another benefit may be gaining a sense of empowerment and confidence in participating in research and having your thoughts and opinions heard.

What if there is a problem?

If there are any complaints about the way the study has been run or how you have been treated during the study, this will be addressed. The detailed information on this is given in Part 2.

Will my taking part in the study be kept confidential?

Yes. Ethical and legal guidelines will be followed to ensure that all information about you, or supplied by you, will be handled in confidence. The details are included in Part 2.

This completes part 1.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2

What will happen if I don't want to carry on with the study?

If you decide that you no longer wished to be part of the study, you have the right to withdraw at any point. This can be after signing the consent forms or even after participating in the conversations. To do so, you would need to contact me using the contact details listed at the bottom of this sheet. If you have already participated in one or both of the interviews, we would like to use the data collected up to the point of your withdrawal.

If you do decide to withdraw from the study, this will have no impact on the care that you or your family or friends receive from the service.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to me and I will do my best to address your concern. If you remain unhappy and wish to complain formally, you can do this by following the NHS Complaints Procedure Details can be obtained from the Oxleas NHS Foundation Trust website. Alternatively you may contact Professor Paul Camic, Research Director, Salomons Centre for Applied Psychology, Canterbury Christ Church University – paul.camic@canterbury.ac.uk.

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This study has been reviewed and given favourable opinion by _____ Research Ethics Committee.

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- Specific information about this research project.

If you would like to speak to me and find out more about the study or have questions about it answered, you can send me an email at laura.chisholm@nhs.net and we can arrange a time to talk through your concerns or queries. Alternatively, you can contact the 24-hour voicemail service on 0330117070 and I will return all calls. To ensure that the message reaches me, state my name: Laura Chisholm and provide your name and telephone number.

To understand more about experience based co-design, please see the following website: www.kingsfund.org.uk

- Advice as to whether you should participate.

Deciding whether to take part in research can take time and often talking this through with someone else can be really helpful. It might be helpful to speak with other members of the experience based co-design project. Another helpful source might be Researchnet, a voluntary group that help conduct helpful research within Oxleas NHS Foundation Trust, as they may be able to talk to you about their own experiences of participating within research.

You can also contact me at laura.chisholm@nhs.net and I will arrange a time to speak with you about the project further.

- If you are unhappy with the study.

If you feel unhappy with the study and would like to speak to me, you can leave a message for me on a 24-hour voicemail phone line at 03330117070. Please say that the message is for me, Laura Chisholm, and leave a contact number so that I can get back to you.

You can also email me at laura.chisholm@nhs.net

However, should you wish to speak to someone other than myself, please email Neil Springham at neil.springham@oxleas.nhs.uk or Professor Paul Camic, Research Director, Salomons Centre for Applied Psychology, Canterbury Christ Church University – paul.camic@canterbury.ac.uk.

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The Bexley Advocacy for NHS Complaints team can also provide further support with registering a complaint and can be contacted by email info@advocacyforall.org.uk and telephone: **020 8300 9666**

Staff Consent form

Study Number:

Participant Identification Number for this study:

CONSENT FORM FOR INITIAL INTERVIEW

Title of Project: A Grounded Theory study exploring the processes involved in an Experience Based Co-Design Project within families

Name of Researcher: Laura Chisholm

Please initial in the box:	
1. I confirm that I have read and understand the information sheet dated..... for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. If I chose to withdraw from the study data collected to that point will still be used within the data analysis. This information will be anonymised, so that I will not be identifiable as a participant.	
3. I understand that data collected during the interviews will be looked at by the lead researcher, Laura Chisholm, the lead supervisor Dr. Sue Holttum and Dr Neil Springham (supervisor). I give permission for these individuals to have access to my data.	
4. I understand that data will be stored on a password encrypted memory stick during the data collection and analysis, and only the lead researcher and supervisors for this project will have access to the passwords. Following the study, I understand that the data will be stored on a password encrypted CD for 10 years before being destroyed.	
5. I agree that my anonymised transcripts can be sent to a reliable transcription service for transcription (typing out the entire interview), to aid with data analysis. There will be no identifiable information on the transcripts prior to them being sent for transcription. Any interviews sent for transcription will be sent on a password protected file via a password protected secure email.	
6. I agree that anonymous quotes from my interview may be used in published reports of the study findings.	
7. I agree to take part in the above study.	

Name of Participant _____ Date _____

Signature _____

Name of Person taking consent _____ Date _____

Signature _____

Appendix B

Semi-structured interview

- What was your experience of participating in EBCD? Can you tell me what it was like? Maybe you could start from when you first got involved. What do you remember about that time?
 - How did you hear about it?
 - Could you tell me more about that – you felt/it seemed...
 - And what happened next?
 - What encouraged you to participate?

- Thinking about your whole experience of EBCD, what would you say were the highs and lows of being involved?
 - Prompt for any lows if not mentioned, or for highs if not mentioned
 - How was participating in the initial interviews?
 - How was participating in the Joint event?
 - How was participating in the co-design groups

- What, if any, were your expectations for the project?
 - So how was the reality of the project the same as what you expected?
 - And how was it different?
 - Are there things that you would have liked to have had more or less involvement with?

Appendix C – Details of the co-design groups

Details of Co-design Groups

Psycho-education

Aim: develop a means of supporting carers to understand the language and context within a mental health setting.

Group membership: two carers, one service user and 7 staff members

Outcome: Psycho-education group for carers.

First Meeting

Aim: develop procedures to support carers' involvement from the first meeting.

Group membership: two carers, one service user and 6 staff members

Outcome: Eco-mapping tool and staff training manual

Confidentiality

Aim: develop a “common sense” approach to confidentiality that supports staff to include carers.

Group membership: one carer, one service user and 5 staff members

Advanced Directive

Aim: develop an initiative to involve carers in the development of advanced directives, and support a solution for their involvement in the care of service users within the realms of confidentiality.

Group membership: one carer, one service user and 5 staff members

Appendix D – Coded Transcript

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Appendix E – Abridged research diary

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Appendix F – Evidence of coding procedure

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Appendix G – Guideline notes for Journal

Guideline notes for Milbank Quarterly Journal

Adapted from: <https://www.milbank.org/quarterly/for-authors/#instructions>

Length

- Text should not exceed 30 pages, excluding abstract, acknowledgments, figures, tables, and references

Formatting

- Double spaced, 12 point font Times New Roman. Paginated pages and line numbers.

Title Pages

- List name of each author in order, including academic degrees and affiliations.

Policy points

- 100 word synopsis of the article's import advancing health policy.

Structure Abstract

- 250-300 words including: context (background, objectives and salience), method (data collection and analysis), findings, conclusions (implications of findings and future research) and keywords.

References

- All sources cited must be properly referenced using *AMA Manual of Style*, 10th edition

Prior to submission

- Authors must complete the ICMJE Form for Disclosure of Potential Conflicts of Interest
- Research must be original work that has not been published previously
- The primary author must transfer copyright to the Milbank Memorial Fund after it is accepted.

Appendix H

Original theory diagram

