COCAPP: Collaborative Care Planning Project

PROTOCOL

Full title of project:

HS&DR Project: 11/2004/12

Cross-national comparative study of recovery-focused mental health care planning and coordination

Short title:

COCAPP: Collaborative Care Planning Project

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Research question

What components need to be in place in order to ensure that care planning and coordination for people with severe mental illness are personalised, collaborative and recovery-focused?

Aims and objectives

Informed by the MRC (2008) framework for developing and evaluating complex interventions, we will identify and describe the theoretical and empirical basis for and the individual components of effective, recovery-focused, care planning and coordination for people with severe mental illness. We will examine the interrelationships between these components and how they may interact to exert an impact on patient outcomes.

In order to develop an exploratory trial aimed at improving patient outcomes, we will collate and synthesise theoretical and empirical data using a range of methods in order to inform and develop a pragmatic and feasible intervention likely to be acceptable to service users, families/carers, practitioners and service managers. To this end we will:

1. Review the international peer-reviewed literature on personalised recovery-oriented care coordination, and compare and contrast the English and Welsh contexts for recovery-based mental health care;
2. Conduct a series of case studies to examine in detail how the needs of people with severe mental illness using community mental health services are assessed, planned and coordinated;
3. Investigate service users', informal carers', practitioners' and managers' views of these processes and how to improve them in line with a personalised, recovery-oriented focus;
4. Measure service user and staff perceptions of recovery oriented practices;
5. Measure service users' views of empowerment and the quality of therapeutic relationships;
6. Identify methods, measures and processes for successfully evaluating a complex intervention aimed at delivering personalised, recovery-focused care planning and coordination and improved patient outcomes.

Background

Across England and Wales, the key vehicle for the provision of recovery-focused, personalised, collaborative community mental health care is the care programme approach (CPA). The CPA is a form of case management introduced in England in 1991, then revised or refocused several times (DH 2008). In Wales the CPA was introduced in 2003 (WAG 2003) and is now – in contrast to England – incorporated into a new statutory framework (WAG 2011). In both countries, the CPA obliges providers to: comprehensively assess health/social care needs and risks; develop a written care and crisis plan with the service user and carer(s); allocate a care coordinator; and regularly review care. CPA processes are now also expected to reflect a philosophy of recovery and to promote personalised care. The concept of recovery in mental health was initially developed by service users and refers to "a way of living a satisfying, hopeful, and contributing life even with limitations caused by illness," while developing new purpose or meaning (Anthony 1993: 527).

The importance of addressing service users' personal recovery, alongside more conventional ideas of clinical recovery (Slade 2009) is now supported in guidance for all key professions (BPS 2000, COT 2006, CNO/DH 2007, RCPsych 2008). To this has been added the more recent idea of personalisation. Underpinned by recovery concepts, this aims to see people and their families taking much more control over their own support and treatment options, alongside new levels of partnership and collaboration between service users (or citizens) and professionals (Duffy 2010: 3). Recovery and personalisation in combination mean practitioners tailoring support and services to fit the specific needs of the individual and enabling social integration through greater involvement of local communities.

Having conducted a preliminary review of the available literature we are able to demonstrate that: 1) There is limited evidence concerning the implementation of the CPA, care planning and coordination; 2) the evidence that does exist suggests that the quality of care planning and coordination is variable and most commonly is NOT collaborative or personalised; 3) little, if any, evidence exists of a recovery focus; and 4) the CPA as currently implemented fails to ensure care planning and coordination is safe, and is seldom valued by service users or carers.

The CPA is central to modern mental health care yet largely missing from the evidence are studies explicitly conducted into the practices of CPA care planning and coordination. Early investigations in England prior to the refocus on recovery, including key studies led by this proposal's chief investigator, drew attention to the bureaucracy associated with care coordination (Simpson, 2003a;

Simpson et al 2003b; Simpson et al 2005), which combined with high caseloads deflected practitioners from therapeutic interventions linked to positive outcomes (Simpson 2005, Burns et al 2007).

National reviews in England report considerable local variation in implementation of CPA and despite improvements in performance, significant numbers of service users not receiving care in line with guidelines (CHAI 2007). A recent Welsh CPA review reflected concerns in: risk assessment, care planning, unmet need and service planning, training, information requirements (including targets) and systems, transfer of care arrangements, and leadership (Elias & Singer 2009). The authors concluded there is a high risk that services are not effectively meeting users' and carers' needs and that significant improvement is required.

Worryingly service users remain largely mystified by the care planning and review process itself. In the most recent national quality survey of over 17,000 community mental health service users across 65 English NHS Trusts, 42% said that their care was coordinated under the CPA (CQC 2011). Over 90% of all respondents described their care as well organised and 83% of those on the CPA knew who their care coordinators were. Yet over half did not understand their care plans; only 16% had written copies; 20% did not think their care plans set out their goals; and 11% did not think their views had been taken into account during care planning. In Wales, 310 users of NHS/local authority mental health services responded to a similar survey (WAO 2011). Only 58% knew who their care coordinator was; just half were given or offered copies of their care plans, with only 51% 'definitely' understanding the content of care plans and 43% 'definitely' involved in 'co-producing' the content.

The need for greater co-production has also been found in the area of risk management. Recent research for the Joseph Rowntree Foundation by co-applicant Faulkner (2012) on service users' views on risk reported that perceptions of risk and rights are significantly different for mental health service users. Practitioners perceive people as a source of risk first rather than being considered potentially at risk in vulnerable situations; they appear to be overlooked by adult safeguarding practices; and their individual rights are compromised by mental health legislation. Co-production, service user involvement and user-led approaches are proposed as ways to ensure that the vision of service users is encapsulated in any policy or service and the delivery, monitoring and evaluation of that service.

This evidence, which points to the relative lack of genuine service user involvement in CPA processes, is significant in the context of what we know about therapeutic relationships and recovery. The therapeutic relationship is a reliable predictor of patient outcomes in mainstream psychiatric care (McCabe & Priebe 2004). Strong, collaborative, working alliances between case managers and people with long-term mental health difficulties have been shown to reduce symptoms, improve levels of functioning and social skills, promote quality of life, enhance medication compliance and raise levels of satisfaction with care received (De Leeuw et al 2011). Yamashita et al (2005) describe negotiating care within a trusting relationship as key in case management and this relationship may influence users' perceptions of stigma (Kondrat & Early 2010).

To summarise: we have demonstrated that the limited available evidence contrasts with the aspiration that care planning and the CPA should be collaborative, personalised and recovery-oriented. In addition, the current approach to assessing and managing risk under the CPA may not be satisfactory for either service providers or service users. This multi-site, cross-national comparative study will benefit the NHS and its users by identifying and describing the factors that ensure CPA care planning and coordination is personalised, recovery-focused and conducted collaboratively. As an exploratory study guided by the MRC (2008) Complex Interventions Framework it will generate empirical data, new theoretical knowledge and greater understanding of the complex relationships between collaborative care planning, recovery and personalisation. It will help identify the key components required and provide an informed rationale for a future planned intervention and evaluation. It will also provide lessons for similar, equally problematic, care planning processes in a range of other health/social care settings (Challis et al 2007).

Methods

Design

We will undertake a cross-national comparative study of recovery-focused mental health care planning and coordination. This two-phase exploratory mixed methods study will produce theory and empirical evidence to inform a future intervention study. Cross-national comparative research involves 'comparisons of political and economic systems …and social structures' (Kohn, 1989: 93) where 'one or more units in two or more societies, cultures or countries are compared in respect of the same concepts and concerning the systematic analysis of phenomena, usually with the intention of explaining them and generalising from them' (Hantrais & Mangen 1996: 1-2). In this study, we will conduct a detailed comparative analysis of ostensibly similar approaches to recovery-focused CPA care planning and coordination within different government, legislative, policy and provider contexts.

In Phase 1, we will conduct a) a review of international literature on care planning and coordination processes and their relationships to recovery and personalisation; and b) a comparative analysis of mental health policy and service frameworks in England and Wales.

In Phase 2, we will conduct six in-depth case study investigations (Stake 1995) across contrasting case study sites in England (n=4) and Wales (n=2).

Phase 1: Literature and policy review and synthesis

Literature review on mental health care planning and coordination processes

We will adopt Greenhalgh et al's (2004) meta-narrative mapping technique (MNM), which focuses on providing a review of evidence that is most useful, rigorous and relevant for service providers and decision-makers and that integrates a wide range of evidence (Dixon-Woods et al 2004). Our MNM review will provide a preliminary map of current mental health care planning and coordination by addressing four questions: 1) how the topic is conceptualised in different research traditions; 2) what the key theories are; 3) what the preferred study designs and approaches are; and 4) what the main empirical findings are.

Using health, social care and other bibliographic databases we will locate international research papers, publications from professional and service user bodies, case studies and other grey literature. We will also supplement our initial electronic searches with other methods (e.g. hand searching of key journals). We will bring together our descriptive map, quality appraisals and focused reviews in the form of a broad narrative synthesis and conclude with an account of those features of care planning and coordination which are associated with an orientation towards recovery and personalisation.

Comparative analysis of policy and service frameworks

Through searching English and Welsh Government websites we will identify all key, current, national-level policy and guidance documents directly relating to mental health care planning and coordination across the two countries, along with those which relate directly to the promotion of recovery and the delivery of personalised care. Drawing on these we will produce a narrative synthesis identifying major themes and areas of policy convergence and divergence, and use these materials to lay out the large-scale (or 'macro-level') national policy contexts to inform our case study research interviews.

Phase 2: Case Studies

Design and theoretical/conceptual framework

We will employ a concurrent mixed methods approach with embedded case studies (Creswell 2009). The study is guided by a theoretical framework emphasising the connections between different 'levels' of organisation (macro/meso/micro). In phase 1 we will study the macro-level through the comparative analysis of English and Welsh policy contexts. In phase 2 concurrent quantitative and qualitative data will be collected at six NHS Trust/Health Board case study sites (meso-level). In each site, access will be secured to a single community mental health team (CMHT) from where six service users will be sampled as micro-level case study subjects. Qualitative data will be generated related to care planning and coordination processes in each.

At the meso-level Trust/Health Board level we aim to:

a) measure service user and staff perceptions of recovery oriented practices;

b) measure service users' views of empowerment and the quality of therapeutic relationships;

c) investigate the subjective views of senior managers and senior practitioners regarding CPA care planning and coordination, recovery and personalisation;

d) identify and review the policy and contextual factors likely to impact on providing personalised, recovery-focused care planning and coordination.

At the micro-level we aim to:

a) explore in detail how the care needs of people with severe mental illness using community mental health services are assessed, planned and coordinated;

b) investigate the subjective views and experiences of service users, carers and care coordinators regarding these processes; and

c) explore how those processes may be improved in line with a focus on personalisation and recovery.

Analysis and interpretation of the case study data will be informed by a conceptual framework that emphasises the connections between different (macro/meso/micro) levels of policy and service organisation, and that draws on the findings of the literature and national policy review.

Setting/context

Community mental health services in England and Wales.

Sampling

We have selected four meso-level NHS Trusts in England and two Local Health Boards in Wales that represent typical, everyday patient populations for whom care coordination, personalisation and recovery present significant opportunities to improve well-being and independence. These sites have been identified to reflect variety in geography and population and include a mix of rural, urban and inner city settings in which routine community care is provided to people with complex and enduring mental health problems from across the spectrum of need.

Within each meso-level Trust/Board site a large sample of service users and care coordinators will be surveyed about recovery oriented practices, empowerment and therapeutic relationships, helping develop a 'Recovery profile' of the organisation. Interview data will also be generated relating to local contexts, policies and practices.

In each Trust/Board site we will also select a single team providing routine community mental health care, and invite a sample of service users to become the starting point for a series of embedded case studies nested within each larger (meso-level) organisational case study. To generate knowledge of how care is planned, coordinated and experienced at the 'micro-level' each service user, their informal carers, and their care coordinator will be interviewed and CPA care plans will be reviewed.

Questionnaires:

Service users (approx n = 66 per site; total n=400) using CMHT services within each Trust/Health Board site will be invited via care coordinators using agreed criteria (e.g. diagnoses, length of contact with service) to complete three questionnaires (see below). This method has been chosen to maximise response rate compared with postal surveys, whilst the target sample size allows for a realistic proportion of refusals.

Care coordinators (approx n = 33 per site; total n=200) across all Trust/Health Board CMHTs will be invited to complete one questionnaire (see below). Target sample size is calculated on approximately 4-6 care coordinators per CMHT x 6 CMHTs in each Trust/Board = 216 in total.

Interviews:
Senior managers (n=2; 12 in total); purposively selected from both health and social care organisations and interviewed to provide information on meso-level contexts CPA policies and practice, recovery and personalisation.

Senior practitioners (n=5; 30 in total); purposively selected to include consultant psychiatrists, senior nurses, psychologists, social workers and occupational therapists and interviewed to provide information on their understandings and experiences of enacting care coordination and planning policies for people using routine community mental health services.

Service users (n=6; 36 in total); purposively selected from CMHT case lists (to include different care coordinators, diagnoses, length of contact with CMHT) and invited to participate and interviewed to provide information on their (micro-level) experiences of receipt of care planning and coordination via care co-ordinators. Specifically we will examine involvement in care, contribution to decisions and shared sense of therapeutic goals. We will also (with appropriate permissions) review their CPA care plans.

Carers (n=4-6; 24-36 in total); with the agreement of the service user, informal carers will be invited to participate in the study. Interviews will focus on how they have been engaged in care coordination and planning by care co-ordinators, whether they have a shared sense of therapeutic goals for their family members and their understanding of arrangements for personalisation and recovery.

Care coordinators (n=6; 36 in total); each service user's care coordinator will be invited to participate and will be interviewed to provide information on experiences of face-to-face care coordination, personalisation and recovery-oriented planning with individuals in receipt of routine community mental health care.

Data collection:

1. Documentation and officially collected data

Local meso-level CPA policy and procedure documents, CQC, national and local audits and reviews, and routinely collected (non-personally identifiable) data (e.g. on local admission, serious incident data).

2. Recovery Self Assessment Scale (RSA) (O'Connell et al 2005)
The RSA is designed to measure the extent to which recovery oriented practices are evident in services. It is a 36-item self-administered questionnaire with service user, family/carer and provider versions. The scale addresses the domains of life goals, involvement, treatment options, choice and individually tailored services. The RSA has been tested for use with people with enduring and complex mental health problems and across a range of ethnic backgrounds. Within each case study organisation, service users (approx n = 66 per site; total n=400) using CMHT services and CMHT care co-ordinators (approx n = 33 per site; total n=200) within each case study organisation will be asked to complete the RSA.

3. The Scale To Assess the Therapeutic Relationship (STAR) (McGuire-Snieckus et al 2007) is a specifically developed, brief (12-item) scale to assess therapeutic relationships in community psychiatry with good psychometric properties and is suitable for use in research and routine care. The subscales measure positive collaborations, positive clinician input and non-supportive clinician input in the patient version. Within each case study organisation, service users (approx n = 66 per site; total n=400) will be asked to complete the STAR, to rate their experience of the therapeutic relationship in relation to promoting recovery.

4. The Empowerment Scale (ES) (Rogers et al, 1997) is a 28-item questionnaire with five distinct sub-scales: self-esteem, power, community activism, optimism and righteous anger. Empowerment is strongly associated with recovery and this is the most widely used scale. It has good psychometric properties. Within each case study site, service users (approx n = 66 per site; total n=400) will be asked to complete the ES to rate their subjective experience of empowerment.

5. Structured interviews with senior managers (total n = 12), senior and 'frontline' practitioners (total n = 66), service users (total n=36), carers (total n=24). Interview schedules will be developed by the study team, informed by the policy/literature review and through consultation with our Project Advisory Group and our Lived Experience Advisory Group. All interviews will explore participants' experiences of care planning and coordination as outlined above. Interviews will be conducted by experienced, specially trained researchers and service user researchers.

6. CPA Care Plan review: within each 'embedded case study' the six purposively selected service user's actual, micro-level, CPA care plan will be systematically reviewed and appraised against a structured template incorporating the identified key concepts of personalisation and recovery (total

n=36). Care plans will also be used to collate demographic, diagnostic and service use data. This information will be used to describe this sample in relation to the wider population of people using community mental health services, for example complexity of case/need.

Data Analysis

Analytical framework:

We will frame our data analysis by drawing on social scientific ideas and on the findings of our Phase 1 evidence and policy review, an approach we have used in previous funded studies (e.g. Hannigan in press). Our concern to explore commonplace practices in community mental health is congruent with interactionist interests in social processes and human action (Atkinson & Housley 2003). This perspective also recognises the importance of social structures, so that in any given setting person-to-person negotiations are shaped by features of organisational context (Strauss 1978). The immediate context for frontline practitioners/care coordinators in this study is the CMHT workplace, each of which we view as a complex, open, system. Each participating team also sits within a larger, meso-level, NHS Trust/Health Board site, which in turn is located within a national-level system of mental health services. This idea of 'nested systems' is a feature of complexity thinking (Byrne 1998), and informs our plan to generate, analyse and connect data at different (but interlocking) macro/meso/micro 'levels' of organisation.

Our Phase 1 policy review will allow us to compare and contrast the largest-scale (or 'macro-level') systems for mental health care across the two countries, and consider the degree to which ideas of recovery and personalisation are represented in prevailing frameworks. We will analyse what senior managers and professionals say, and write, about care planning and coordination across participating sites to make the connections between the 'macro' and the 'meso', and in the first instance we will present a detailed account of our six different local organisational contexts in within-case fashion (Ayres et al 2003). The most important phase of our data analysis will be our exploration of what frontline practitioners, service users and carers say, and write, about how actual, individual (or 'micro')-level care is planned and coordinated. We will establish the day-to-day realities of how care is planned, coordinated and experienced and the degree to which processes and actions reflect orientations to recovery and personalisation.

Analysis:

Quantitative data: Coded, anonymous data on patient demographics, diagnosis and service use will be entered onto an Access spreadsheet and then checked for errors and omissions and corrected against records where possible. Questionnaire data will be entered onto SPSS, then checked and cleaned by a second researcher prior to statistical analysis. Total scores, means and standard deviations will be derived to produce a 'recovery profile' for each site and One Way Analysis of Variance conducted to compare differences between the six sites on the RSA, STAR and ES measures. If significant differences are found Tukey's post hoc test will be conducted to ascertain which measures differ between which locations. Correlations will be carried out to identify if there is a relationship between recovery-oriented focus, empowerment and the quality of therapeutic relationship amongst patients.

Qualitative data: All interview data will be professionally transcribed, checked by researchers against the digital recordings and imported into QSR NVivo for organisation, charting and analysis using Framework method. Framework is a form of deductive qualitative analysis developed specifically for applied or policy relevant analysis (Ritchie & Spencer, 1993). Data extraction and charting will be undertaken independently by two RAs who then check each other's summaries against the original transcripts. Framework allows higher-level analysis and refining of concepts to be undertaken by researchers at different sites. Framework will be employed to explore the relational aspects of care planning and coordination, the degree to which service users and carers participate in CPA processes and decision-making, and the extent to which practitioners are oriented towards recovery and personalised care.

Triangulation: From our detailed examination of the international evidence, and from our inspection of new quantitative results and qualitative findings at interlocking macro, meso and micro-levels, we will provide an analysis and interpretation of those aspects of policy, organisational context and human action which appear most closely associated with recovery-informed and personalised care planning and coordination.

Plan of investigation and timetable

The study will take place over 24 months with six months allowed for obtaining ethics and R&D approvals, recruiting and training staff.

Approval by Ethics Committees

This study will require NHS Research Ethics Committee approval which we will apply for as soon as we receive a funding decision. Once funded we will secure Mental Health Research Network (MHRN) registration and Mental Health Research Network Cymru (MHRNC) project registration in Wales. In each case we expect to receive assistance with necessary approvals (such as ethics and research governance, including research passports) across both English and Welsh sites.

All case study participants will be given detailed written information on the study and asked to provide written consent. Consent will be assumed in the case of participants choosing to return completed standardised questionnaire measures. All participants will be assured of anonymity in the use of their data. Participants will be informed that research interviews will be audio-recorded, transcribed and all identifying material such as names or place names will be removed to protect their confidentiality. Participants will be free to withdraw at any time without consequence to their treatment or employment status. We do not anticipate any risks to individuals from participation in this research but should anyone become distressed we will terminate the research interview and make arrangements with their treatment team to offer further support.

Project management

Professor Alan Simpson will lead the project and the England arm of the study. He will liaise closely with Dr Ben Hannigan who will lead the Wales arm of the study. Dr Julie Rowe will be employed under Prof Simpson as project manager in line with HS&DR recommendations and will liaise with the PI in London and project lead in Wales and coordinate operations across all sites.

Project team meetings will be held at least six-monthly during the study, supplemented with frequent online/telephone communications. An expert Project Advisory Group (PAG) will be established and will include senior academic researchers, senior health service managers and experienced service user research representatives. The PAG will meet at least four times during the study to monitor progress, ensure milestones are met and advise on any challenges. In addition, a Lived Experience Advisory Group of service users and carers will be established and meet at least four times with the study team.

Public contributor/public involvement

The outline and full proposals have been developed in consultation with an NIHR-funded service user research advisory group (SUGAR), established and facilitated by the lead applicant. In addition, co-applicant Alison Faulkner is a highly respected and published service user researcher who has contributed to the design of the study and will play a central part throughout the study. Alongside the Project Advisory Group (see above) we will establish a Lived Experience Advisory Group (LEAG) of service users and carers which will meet at least four times with the study team to discuss and advise on the development of the study and findings from a service user/carer perspective and to feed into the Project Advisory Group. We will consult with this group throughout the project as follows:

1. We will present the findings of the literature/policy review to LEAG and invite them to help develop the conceptual framework and content of the questions for the interview stage of the study.

2. During the Framework analysis of the interview data, LEAG will be invited to collaborate on refining initial dimensions or categories and subsequent themes (following a similar process recently led by the PI on his peer support study).

Service user researchers (SURs): Four SURs will be trained and supported by Alison Faulkner with other members of the research team to undertake the interviews of service users and carers with the support if required. The SURs will be required to have regular individual supervision with AF and to attend group supervision/support. At each case study site, one or two SURs will visit the site with the RA and jointly make contact and initial introductions and then organise their work together.

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