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Collaborative



Care Planning

Impact or Impasse?

PPI in a cross-national study of recovery-focused care planning

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Patient and Public Involvement in Research:
The Art of Engagement



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Overview

- Brief overview of a cross-national research study
- Highlight the approaches used to involve and collaborate with service users and carers
- Identify some of the impacts and successes
- Discuss some of the challenges and lessons learned

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

- Care Planning and Coordination in England and Wales
- Care Programme Approach(CPA)/Care and Treatment Planning (CTP) underpins care planning and coordination
- Both supposed to be:
 - Implemented in partnership
 - Recovery-focused
 - Personalised
- *Recovery and personalisation in combination mean practitioners tailoring support and services to fit the specific needs of the individual; individuals taking more control over their condition and lives; and enabling social integration through greater involvement of local communities.*
- Very little research undertaken in this area



Aims

- To identify and describe the factors that facilitate or hinder the delivery of personalised, recovery-focused care planning and coordination for people with severe mental illness

Design

- Cross-national comparative study of care planning in community mental health - mixed methods with embedded case studies
- Guided by a theoretical framework emphasising the connections between different 'levels' of organisation (macro/meso/micro) (Byrne 1998)
- Phase 1: Meta-narrative review of peer-reviewed literature and English and Welsh policies (macro-level).
- Phase 2: In-depth case study investigations across six contrasting case study sites in England (n=4) and Wales (n=2) with range of urban, rural and inner city populations (0.5-1.6m)
- Employing mixed methods with embedded case studies (meso and micro levels) (Creswell 2009, Stake 1995).



Methods and data collection

- Questionnaires

- 449/400 Service users – random sample; response rate 9.2% -19.6%
- 205/200 Care co-ordinators – total population

- Interviews (118 completed /138 target number)

- 12/12 Senior managers (2 per site)
- 27/30 Senior practitioners (5 per site)
- 33/36 Service users (6 per site/one CMHT)
- 29/36 Care coordinators (6 per site/one CMHT)
- 17/24 Carers (4 per site/one CMHT)

- Care Plan Reviews

- 33/36 Care plans

- Analysis

- Quantitative data – various statistical analyses using SPSS vs21
- Qualitative data – summarising, charting, précising using Framework method, QSR NVivo10 & Excel

Integration and synthesis of datasets

Used Framework to **combine charted summaries** of qualitative data alongside **summary statistics** of quantitative measures for each case study site.

Armed with our set of six within-case analyses we then conducted a **cross-case analysis** to draw out key findings from across all sites.

Investigate the data to identify 'evidence' at the **intersections** between **macro-meso-micro levels** and **underpinning framework**:

	Local context/ background	CPA/CTP Care Planning	Recovery	Personalisation
Macro-level (national policy, regional drivers)				
Meso-level (Trust/Board policies; senior manager /practitioner interv'ws)				
Micro-level (service delivery - user/ carer/ care coordinator experiences)				

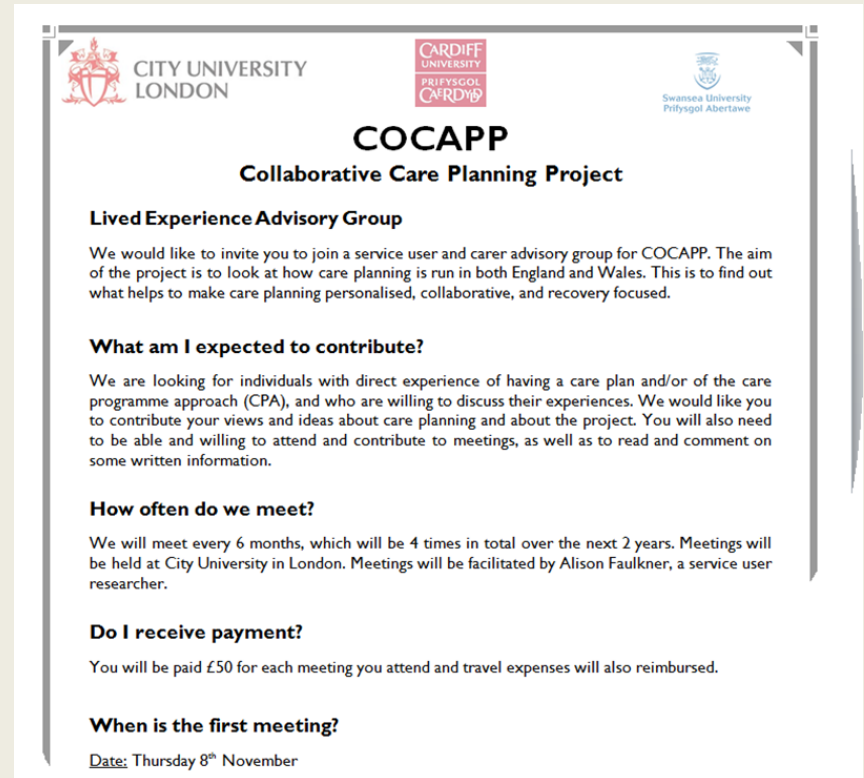
Figure: Theoretical matrix underpinning the Framework analysis

PPI in COCAPP

- Alison Faulkner, Independent Service User Researcher
 - co-applicant and co-investigator
- Consultation with Service User and Carer Group Advising on Research (SUGAR)
- Lived Experience Advisory Group (LEAG)
- Project Steering Group (PSG)
- Service User Researchers (SURAs) / Service User Project Assistants (SUPAs)

Lived Experience Advisory Group (LEAG)

- Role description and person specification
- National recruitment
- Payment & travel costs
- 5 meetings over 24 months
- 10 members (north and south Wales, north England, Midlands, Sussex and London)
- Facilitated: Alison Faulkner



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COCAPP

Collaborative Care Planning Project

Lived Experience Advisory Group

We would like to invite you to join a service user and carer advisory group for COCAPP. The aim of the project is to look at how care planning is run in both England and Wales. This is to find out what helps to make care planning personalised, collaborative, and recovery focused.

What am I expected to contribute?

We are looking for individuals with direct experience of having a care plan and/or of the care programme approach (CPA), and who are willing to discuss their experiences. We would like you to contribute your views and ideas about care planning and about the project. You will also need to be able and willing to attend and contribute to meetings, as well as to read and comment on some written information.

How often do we meet?

We will meet every 6 months, which will be 4 times in total over the next 2 years. Meetings will be held at City University in London. Meetings will be facilitated by Alison Faulkner, a service user researcher.

Do I receive payment?

You will be paid £50 for each meeting you attend and travel expenses will also be reimbursed.

When is the first meeting?

Date: Thursday 8th November

How it worked

- Ground rules agreed
- PI and several researchers attended
- Presentations, updates, discussions, questioning, drawing on lived experiences
- SURAs presentation/discussion
- Minutes & action points circulated to team
- Alison and 2 members attended and reported to Project Steering Committee

Contributions and impact

- Explored good practice in care planning
 - Suggestions for recruitment
 - Suggestions for interview topics and questions
 - Recommended changes to interview schedules
 - Suggestions re sensitive issues and potential upset
 - Some exploration of initial findings
- What to look for in practice
 - Informed recruitment plans
 - Included in all interview schedules
 - Changes adopted
 - Informed ethics application and practice
 - Minimal input into report

LEAG challenges

- Overall – positive experience for LEAG members and team but...
- Contribute service user literature to literature review
 - Did not really happen despite reminders
- Limited input into analysis/interpretation
 - Project running late
 - Team overload
- Lack of communication from research team between meetings
 - Newsletter/Facebook suggested; noted for new study
- Expensive
 - Travel/accommodation for distant members exceeded budget
 - Realistic budgets needed and/or smaller group
- Timing
 - Working meetings around data collection, analysis and PSG meetings difficult
 - More planning required
 - Difficult to anticipate changing project landscape and to have sufficient flexibility

Service User Research Assistants (SURAs) Service User Project Assistants (SUPAs)

- 3 in England; 2 in Wales
- Recruited via MHRN/MHRN-C
- Role description/Person specification
- Pay & expenses
- Training & support
- 36 service user interviews (6 per site)
- 24-36 carer interviews (4-6 per site)

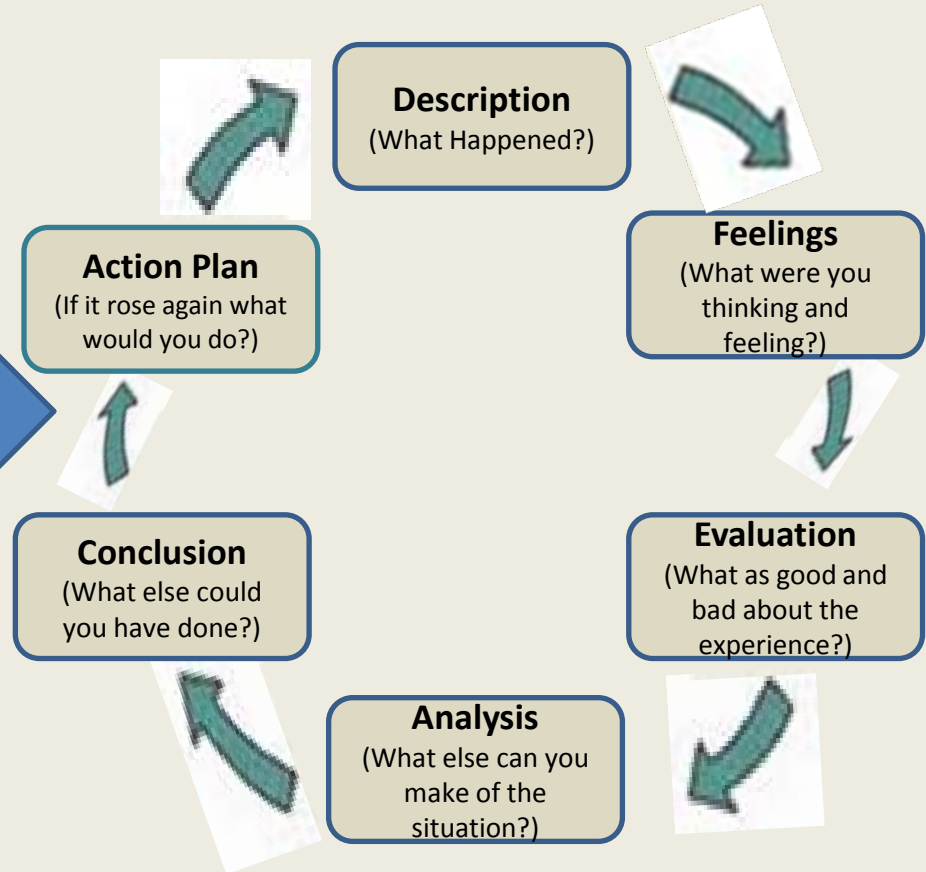


How it worked

- **Training & preparation**
 - Alison & members of team
 - 1.5 day workshops
 - Drawing and building on previous experiences
 - Sharing experiences and knowledge
 - Expectations. concerns
 - Interviewing, challenges
 - Role play
- **Joint working** with several RF/RAs
- **Flexible approach** depending on skills and confidence
- **Support**
 - Ongoing during joint working
 - Time between visits
 - Journeys to and from
 - Input from AF and PI

Gibbs' Reflective Cycle

- “After the interview, I filled in the Gibbs Reflective Cycle which is filled in after every interview.
- This cycle makes you think about the interview contents by asking your feelings, evaluation, analysis, and conclusion and action plan...
- I think this reflective cycle is a very useful tool that will help you improve your interview technique.”



Reflections from the SURAs

Highlights

- ‘The Privilege of hearing someone’s story and also hearing the story from two sides [service user and carer] brings added insight (DH).
- ‘It was good to spend time talking to the researcher in the day, knowing someone better helps to feel part of the team’ (DH).
- ‘Being involved in COCAPP has given me lots of confidence and the team are very supportive and fun’(KB).
- ‘I liked working in a pair with the research assistant’ (JT).
- ‘Able to discuss and share concerns about vulnerable service users’ (JT)

Challenges

- ‘Trying to prevent interview hopping when interviewing the service user and carer in the same day’ (JT).
- ‘Delay in time between the training and first interview was considerable’ (DH).
- ‘Getting used to having someone else in on the interview (having the RA present)’ (DH).
- ‘Challenges when first language is not English’ (DH).
- ‘Receiving and interpreting feedback from the researcher (DH).

Reflections from the SUPAs

- Identity as a Service User Researcher and self-disclosure
- Reacting to and coping with potentially distressing disclosures by research participants
- Managing expectations & ad hoc nature of work



- Recruitment & Research Passports
- Involvement primarily in data collection – not all stages of the research process

More reflections from the SUPAs

- Very supportive team – willing to be flexible and viewed SUPAs as equals
- Fluctuating nature of own mental health condition
- Providing real opportunities to develop as a researchers
- Providing training appropriate to the needs and experience of SUPAs – we are all very different



Reflections from RF/RAs

Highlights

- Seeing the natural flow of the interview
- Learning interview skills from the SURA/SUPAs
- To see the SURA/SUPAs grow in confidence
- Spending time with the SURA/SUPAs
- To see the SUs that are interviewed see hope in recovery from the SURA/SUPAs

Challenges

- Preparation – setting up payments and governance procedures
- Scheduling – trying to coordinate three or four people for an interview
- Travel – sometimes long days which involved emotional interviews and debriefing in between the interviews
- Providing feedback sensitively to the SURs and facilitating the process when the interview veered off track
- Additional pressure – less ‘switch off time’

Reflections as Principal Investigator

- Committed to greater PPI and see the value in so many ways
- Logistical and bureaucratic challenges of employing SURs remains – getting worse? – easiest to employ on full contracts but not available or desirable for all SURs
- Funding and employment restraints make flexible responses to situations difficult
- Anticipating and adapting to developments in projects – e.g. delays, recruitment difficulties, staff absence - more difficult when considering SUR needs
- Building in extra time to fully engage with SURs in all aspects of study difficult when other pressures on, e.g. overdue final report; obtaining funds for new projects – easy to become ‘blinkered’ (just me?!)

Conclusions

- When planning/writing project plans
 - Build and cost in time for all staff to be working with SURs e.g. on analysis (but will raise costs of projects – risky)
 - Ensure time, space, processes for ongoing support and reflection for all staff – to include the additional pressures of working collaboratively
- Lobby research funders for greater appreciation and support for ‘real PPI’ in studies



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Thank you

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