

Training to enhance user and carer involvement in mental health-care planning: the EQUIP research programme including a cluster RCT

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Disclaimer: This report contains transcripts of interviews conducted in the course of the research and contains language that may offend some readers.

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Scientific summary

The EQUIP research programme

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Scientific summary

Background

Evidence is accumulating to confirm that increased service user and carer involvement can lead to positive outcomes for both health-care systems and their users. Care planning is one area of contemporary practice that is conducive to service user involvement. Although principles of service user and carer involvement are embedded in policy ideologies, research has found that they have been suboptimally translated in practice. Service users and carers consistently report feeling unsupported by care planning processes and continue to request greater involvement in their care.

Identified barriers to service user and carer involvement in mental health services include poor information exchange, ritualised practices that limit opportunities for involvement, inhibitions or misconceptions regarding patient confidentiality and/or professional resistance to sharing decision-making power. Our systematic review found conceptual differences in the interpretation and meaning of involvement between service users and professionals. Although professionals tended to focus on objective evidence of service user involvement, such as ensuring that care plans were shared with and signed by service users, service users and carers tended to prioritise the qualitative experience of their involvement, specifically the consistency and quality of their care planning relationships.

If meaningful service user and carer involvement in care planning is to be achieved, there is a pressing need to agree and foster a system-wide, user-centred model of collaboration and involvement. Our research programme aimed to address the gap between policy and practice by addressing this need.

Aims and objectives

The aim of the programme grant was to improve service user and carer involvement in care planning in mental health services. We created a programme of work to address this by designing, evaluating, implementing and disseminating a training intervention for mental health professionals, which was co-designed and co-delivered with service users and carers.

Our programme had four separate but inter-related workstreams.

Workstream 1

- Co-develop and co-deliver a training intervention for health professionals in community mental health teams to enhance service user- and carer-involved care planning.
- Develop a patient-reported outcome measure of service user involvement in care planning, develop an audit tool and assess individual preferences for key aspects of care planning involvement.

Workstream 2

- Evaluate the clinical effectiveness and cost-effectiveness of the training intervention to enhance service user- and carer-involved care planning in secondary care mental health services.

Workstream 3

- Understand the contextual, individual and organisational barriers and facilitators, and examine the processes involved in the development and use of service user- and carer-involved care planning.

Workstream 4

- Disseminate our training intervention materials and patient-mediated resources produced during the programme to all relevant stakeholders using multiple methods.

Methods and results

Workstream 1

Development of training intervention

Nine focus groups (four with service users and carers, four with health professionals and one mixed group) involving 17 service users, 16 carers and 23 health professionals were undertaken to inform the content, length and delivery mode of the service user- and carer-led training package. Seventy-four individual qualitative interviews with service users ($n = 25$), carers ($n = 21$) and health professionals ($n = 28$) were conducted to determine the priorities and core concepts underpinning service user and carer engagement and involvement in care planning. Data from the focus groups and interviews were combined and analysed using framework analysis, and then synthesised alongside evidence gathered from a scoping review of systematic reviews of successful training implementation to develop the training intervention. We trained service users and carers to co-deliver the training intervention to health professionals working in community mental health teams.

Development of the patient-reported outcome measure and audit tool

We conducted a systematic review reporting the use, development and validation of user- and carer-reported outcome measures, which confirmed the need for a new patient-reported outcome measure to be developed. Potential items for the patient-reported outcome measure were generated from data collected in the focus groups and interviews described above and examined for validity by members of the service user and carer advisory group through cognitive interviewing. Testing of the resultant 61-item patient-reported outcome measure was completed with 402 service users and carers, followed by a second round of completion by a random sample of 59 participants to measure test–retest validity. Detailed psychometric and statistical analysis was conducted using classical test, Mokken and Rasch analyses, and a final 14-item patient-reported outcome measure was produced, providing a unidimensional measure of service user and carer involvement in the mental health-care-planning process.

We developed an audit tool to inform clinicians, services, auditors and researchers who want to quantify levels of user and carer involvement in care planning. For the audit tool, we completed a three-round consensus exercise with our service user and carer advisory group ($n = 16$) and reduced the 61 candidate patient-reported outcome measure items to form a shorter six-item audit tool. Psychometric analysis assessed the performance of the audit tool using a combination of classical test, Mokken and Rasch analyses. Test–retest reliability was calculated using t -tests of interval level scores between baseline assessments and the 2- and 4-week follow-ups.

Stated preference study

We completed a stated preference survey to assess the strength of user and carer preferences and weights for key items included in the audit tool. We used a binary discrete choice experiment with five attributes (whether or not preferences for care are included in the care plan, whether or not the care plan helps me manage risk, completeness of the information in the care plan, whether or not important decisions are explained to me and whether or not all important aspects of my life are catered for) and an additional attribute describing the time per person spent on care-planning-related activities. We recruited 232 service users and carers, of which 89% completed all choice questions. Most responses were from service users ($n = 166$, 72%), of whom 34 (20%) also identified themselves as carers. Mixed logit regression results demonstrated that preferences were strongest for the attribute 'my preferences for care are included in the care plan'. The least preferred attribute was whether or not the information included in the care plan was complete.

Workstream 2

A pragmatic cluster trial with community mental health teams in England was designed to evaluate the clinical effectiveness and cost-effectiveness of the training intervention developed in workstream 1. The trial used cohort and cross-sectional samples to minimise threats to validity.

The cluster cohort was recruited at baseline and followed over the 6 months of the trial, and the cluster cross-section was recruited at the end of the trial. Consenting service users cared for by each community mental health team were recruited, and carers were recruited from consenting service users. Each community mental health team was randomised to either the intervention (training in care planning) or control (usual-care planning). The community mental health teams randomised to the intervention received the training package.

The primary outcome was service user self-reported 'autonomy support' measured using the Health Care Climate Questionnaire.

Secondary outcomes included patient self-reported involvement in decisions [Enhancing the Quality of User and Carer Involvement in Care Planning (EQUIP) patient-reported outcome measure], satisfaction with services (Verona Service Satisfaction Scale); side effects of antipsychotic medication (Glasgow Antipsychotic Side Effect Scale); well-being (Warwick–Edinburgh Mental Wellbeing Scale); recovery and hope (Developing Recovery Enhancing Environment Measure); anxiety and depression (Hospital Anxiety and Depression Scale); alliance and engagement (California Psychotherapy Alliance Scale); quality of life (World Health Organization Quality of Life questionnaire); carer satisfaction (Carer and User Expectations of Services); quality-adjusted life-years (EuroQol-5 Dimensions, five-level version); and use of health-care services. Measures were completed at baseline (pre training) and at 6 months post training (cohort), and at 6 months post training only (cross-sectional). Satisfaction with the training by health professionals was measured using the Training Acceptability Rating Scale.

We randomised 36 (intervention, $n = 18$; usual care, $n = 18$) community mental health teams in 10 NHS trusts in England and co-delivered our training intervention to 350 mental health professionals, of whom 304 were care co-ordinators. We recruited 604 service users with serious mental illness and 90 carers under the care of community mental health teams into the cluster trial, with 82% retention at the 6-month follow-up. A further 682 participants were recruited to the cross-sectional study. Training was deemed highly acceptable by health professionals. The results showed no statistically significant difference in the primary outcome (Health Care Climate Questionnaire) (adjusted mean difference -0.064 , 95% confidence interval -0.343 to 0.215 ; $p = 0.654$) or other outcomes between intervention and usual care at the 6-month follow-up.

Overall, the training intervention was associated with a net saving of $-\pounds 54.00$ (95% confidence interval $-\pounds 193.00$ to $\pounds 84.00$), with a net quality-adjusted life-year loss of -0.014 (95% confidence interval -0.034 to 0.005). The 95% confidence intervals of the net differences cross zero, indicating that there was no evidence that the costs or health benefit differed between the training intervention and control. There was a net saving per quality-adjusted life-year lost of $\pounds 3600$. Whether or not the savings offset the quality-adjusted life-year loss depends on the decision-makers' willingness to pay to gain 1 quality-adjusted life-year. If decision-makers are willing to pay $\pounds 5000$ – $15,000$ to gain 1 quality-adjusted life-year, then the probability that the training intervention was cost-effective was between 0.16 and 0.41. This ranged between 0.09 and 0.65 in the sensitivity analyses using the quality-adjusted life-year. The training was positively evaluated, with the inclusion of service users and carers delivering the training as the most valued aspect.

Workstream 3

We conducted a preimplementation qualitative study prior to the development of the training package. This aimed to understand the organisational structures, influences, context and policies relating to care planning within mental health services in order to feed into the intervention design and to increase the likelihood of it being implemented in normal practice. This complemented the analysis in workstream 1 and involved a mapping exercise of contemporary care planning policies as well as 13 semistructured interviews with key

informants involved locally and nationally in policy, practice and research. Interviews were analysed using normalisation process theory, which complemented the data collected during workstream 1.

We conducted a nested longitudinal qualitative process evaluation using multiple methods to complement and supplement the evidence provided by the cluster trial in workstream 2. A series of interviews were undertaken with service users ($n = 29$), professionals ($n = 21$) and carers ($n = 4$) from both the usual-care and the intervention arms of the cluster trial at three time points (baseline and 6 and 12 months post intervention). Data were analysed thematically to obtain an in-depth understanding of staff experiences of receiving and utilising the EQUIP intervention and to examine changes to practice over time.

The results demonstrated that, despite buy-in from those delivering care planning in mental health services, there was a failure of training to become embedded and normalised in local provision. This was attributable to a lack of organisational readiness to accept change, combined with an underestimation and lack of investment in the amount of relational work required to successfully enact the intervention.

Workstream 4

We disseminated our training intervention materials and patient-mediated resources produced during the programme using multiple methods.

‘Willing Adopters’

Mental health trusts involved in the programme were invited to become ‘Willing Adopters’ following the completion of workstream 2. Trusts negotiated a range of options for engagement, including delivery of the training to other community mental health teams or teams in the trust, a ‘train the trainers’ course for health professionals, service users and carers to deliver the training package within their trust, patient-mediated materials developed through the programme, and the audit tool for trusts to measure service user and carer involvement in care planning before and after training. The ‘Willing Adopters’ programme was delivered in seven NHS mental health trusts, with each trust opting for a variation on which components they wished to adopt. The EQUIP ‘Willing Adopters’ training was delivered to 192 attendees (staff members, $n = 177$; service users and carers, $n = 15$) in addition to the roll-out by some of the NHS trusts. Acceptability of training demonstrated high levels of overall satisfaction. Trusts that implemented the EQUIP ‘Willing Adopters’ programme have shown some promising results with changes in Care Quality Commission ratings.

Dissemination

We developed multiple methods to disseminate our findings, including two animations detailing findings from workstream 1 based on the ‘10 Cs of care planning’, which included our National Institute for Health Research award-winning animation about carers’ perspectives of care planning. To maximise impact and increase the reach of the animations, a targeted approach to promotion via social media was employed alongside individual events, such as a Reddit (San Francisco, CA, USA) ‘Ask Me Anything’ session, which achieved a reach of almost 9 million.

We also developed ‘EQUIP cards’: pocket-sized fold-out cards designed for service users and carers, which contained useful information and prompts to support involvement in care planning decisions. We have distributed over 50,000 EQUIP cards and posters to service users, carers and mental health staff involved in care planning via mail-outs to NHS trusts and third-sector organisations, and directly to service users alongside appointment letters for care planning meetings. A video was developed by the service user and carer advisory group with Patient Voices (Programme Pilgrim Projects Ltd, Landbeach, UK) to disseminate findings from the entire programme.

Conclusions

We co-developed and co-delivered (with service users and carers) a highly acceptable training intervention for health professionals working in community mental health teams with people with serious mental illness.

We developed a 14-item patient-reported outcome measure, 'Enhancing the Quality of User and Carer Involvement in Care Planning' scale, which displays excellent psychometric properties and is capable of unidimensional linear measurement. We developed a validated six-item audit tool to inform clinicians, services, auditors and researchers who want to quantify levels of user and carer involvement in care planning. Our stated preference study found that service users and carers are willing to spend time improving the way in which they are involved in their care planning. These findings could be used to help services target improvements in care planning to the aspects most important to service users.

Despite high levels of satisfaction with the training, our pragmatic cluster trial with cohort and cross-sectional samples found no significant effect between community mental health teams receiving the training and those not receiving the training. There was no evidence that the costs or health benefit differed between the training intervention and the control. There was a failure of training to become embedded and normalised in local provision. This was caused by a lack of organisational readiness to accept change, combined with an underestimation and lack of investment in the amount of relational work required to successfully enact the intervention. Our in-depth qualitative work and process evaluation showed consistent deficits in care planning involvement. We used a systematic approach to disseminate our results and have rolled out the training, patient-mediated materials and resources to NHS trusts. We have filled a training gap to encourage shared understanding and language between services users and carers.

Our inability to show an effect of the training may in part be explained by data from our qualitative process evaluation, which suggested that, despite ideological buy-in from trained staff, our training failed to become embedded and normalised in local provision. Supervision sessions were offered to staff post training but demonstrated very low uptake. This widespread failure to engage in supervision may in part reflect the fact that professionals' work priorities, workload and availability were not conducive to incorporating new knowledge and skills from training into their existing role. Qualitative data collected at the 6- and 12-month follow-ups suggested that there was an absence of organisational readiness to accept change and an underestimation of and deficient investment in the amount of relational work required to make it successful. This combination of stretched staff and services, in the absence of organisational requirement and support to incorporate training into usual practice, most probably had an impact on the probability of eliciting measurable changes in service user and carer involvement. Our 'Willing Adopters' programme with enhanced organisational buy-in and support has demonstrated promising results with Care Quality Commission changes.

Recommendations for research

- There remains an urgent need to develop ways of improving service user and carer involvement in their care plans. More complex, comprehensive and enduring interventions may be required, such as the use of incentives, linkage to routine outcome monitoring and better integration into routine clinical systems. However, such comprehensive models raise significant challenges for their implementation (and their assessment in a rigorous, controlled fashion).
- Research should focus on developing and evaluating new organisational initiatives to address contextual barriers to service and carer involvement in care planning. These initiatives should include the introduction of both 'bottom-up' and 'top-down' structural changes, such as accountability systems, as well as system-level strategies that encourage or facilitate shared access to care plans.

Trial registration

This trial is registered as ISRCTN16488358.

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