

## Co-designing strategies with community partners in an umbrella review

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**Abstract:** Meaningful involvement of community members in evidence synthesis remains under-described. This study reflects on engaging two Community Co-Researchers with lived experience in the screening, data extraction, validation, interpretation, and dissemination of an umbrella review. Their participation was supported through flexible engagement, task-specific training, and ongoing communication. The findings suggest that careful recruitment, clear roles, capacity-building, and collaborative processes are important for reducing tokenism and enabling lived experience to meaningfully inform evidence synthesis.

### Background and Aims

Community-engaged research is increasingly recognized as important in health research.<sup>1,2</sup> This approach involves partnering with community members with lived experience to enhance the relevance, accountability, and real-world impact of research.<sup>3,4</sup> However, there is limited practical guidance on how to engage community members meaningfully in evidence synthesis. This study reflects on the process of engaging community members as co-researchers in an umbrella review and examines how their involvement shaped each step of the review process. It also responds to the growing call for more transparent, equitable, and non-tokenistic approaches to patient and public involvement in knowledge co-production.<sup>5</sup> By documenting practical lessons from this process, we aimed to identify strategies that can support meaningful collaboration and improve the usefulness of research findings for both communities and decision-makers.

### Approach

Two community members were engaged as Community Co-Researchers (CCRs) throughout the umbrella review process. Their contributions included refining screening criteria, helping resolve disagreements during the screening of 390 abstracts and 85 full-text articles, and validating data extraction across 12 included studies. They also contributed to the interpretation and synthesis of findings by mapping the barriers under a pre-specified framework, and providing contextual insights grounded in lived experience. In addition, CCRs co-presented findings at a conference and helped guide dissemination strategies for public and rightsholder audiences. To support

meaningful participation, capability-bridging activities were integrated throughout the review process.<sup>2</sup> Onboarding conversations identified CCR motivations and practical participation barriers, including time, family and work commitments, and technology access. Early meetings established engagement norms, including plain-language communication and clear decision points. Meetings followed a consistent structure with progress updates, focused questions, and areas requiring CCR input. Communication through Zoom, WhatsApp, email, and Google Drive supported ongoing engagement. Post-meeting summaries documented decisions, next steps, and how CCR feedback informed the review. Task-specific training supported confident participation.

### Key Reflections

Meaningful engagement was supported through flexible and accessible processes, including training, plain-language materials, regular communication, and meetings scheduled around CCR availability. These strategies enabled sustained involvement across review stages. CCR contributions strengthened the review by helping verify screening decisions, validate extracted information, and identify issues that were insufficiently captured in the literature. Their lived-experience insights enriched interpretation by grounding the findings in community realities, highlighting overlooked barriers, and improving the practical relevance and accessibility of the review for community and stakeholder audiences. The process also highlighted the importance of intentional recruitment and onboarding, early discussion of roles and expectations, and structured communication that enabled CCRs to contribute to both technical review tasks and interpretive decisions. Embedding accessibility supports within the review process

and documenting how CCR input influenced decisions helped ensure that engagement remained meaningful rather than symbolic.

## Conclusion

Co-producing an umbrella review with CCRs is both feasible and valuable when grounded in clarity, flexibility, and shared ownership. Structured approaches to recruitment, onboarding, capacity-building, and collaborative decision-making can support meaningful engagement and reduce tokenism. Adopting a co-design mindset, where community partners contribute to planning, conducting, and disseminating the review, can further strengthen the role of lived experience in shaping evidence synthesis. Embedding lived experience throughout evidence synthesis can strengthen methodological quality, improve interpretive depth, and enhance the relevance and impact of review findings.

## References

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