A review of the roles of community members and patients beyond advising in the research process

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Community members (i.e., community advisory boards or CABs) give researchers priceless insight about community needs, cultural norms, and health practices. Typically, CABs inform the early stages of a research project including the explication of needs and design of the intervention. However, the role of community members and patients beyond that of advising and as full members of the research team, is still unclear. This gap needs to be addressed because funding agencies are demanding that community members and patients be involved in all aspects of the research process. Hence, before we began our community intervention we reviewed the literature to explore what has been written about CAB’s role in research. We examined the: 1) researcher’s primary purpose in collaborating with a CAB, 2) tasks completed by the CAB, 3) frequency of CAB meetings, and 4) reimbursement to CABs. We searched the PsycINFO, PUBMED, and CINAHL databases using the search terms community advisory boards, intervention development, patient advisory board, and health advisory board-including and analyzing 25 articles. Content analyses revealed the following: 1 and 2) The researcher’s primary purpose and the tasks designated to CAB members were similar. Common tasks include providing education, building relationships and trust between researchers and participants, and evaluating intervention outcomes. 3) Frequency of the CAB meetings ranged from at least monthly to yearly; most common was monthly. 4) Reimbursement varied from a stipend to training/education to hourly pay. Based on our review, there appears to very limited information or clarity on the role of community members on research teams beyond simply advising. Future research needs to clearly document roles, duration of roles, and compensation for community members as co-investigators or members of research teams. We need this information to meet the national calls for research that fully involves the community members and patients that we serve.

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