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Title

Permission to contact patients for research participation: A scoping review

Priority 1 (Research Category)

Research Capacity Building

Presenters

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Abstract

CONTEXT. Recruitment of participants into clinical research poses a significant challenge, with many studies failing to reach recruitment targets, resulting in financial losses and the non-realization of potential benefits for patients. To overcome these issues, several innovative recruitment strategies have been developed, including permission to contact patients for research. This approach involves patients giving permission to be contacted directly by a research team to be invited in a research project, without going through an intermediary (e.g., a family physician).

OBJECTIVE. To explore the characteristics and impact of permission to contact approaches. Specifically, we studied the impact, benefits, risks, implementation facilitators and barriers of such approaches in healthcare settings, including primary care.

STUDY DESIGN AND ANALYSIS. We carried out a scoping review as per the methods of the Johanna Briggs Institute. Two reviewers independently and systematically reviewed titles, abstracts, and full-text articles. One reviewer performed data extraction, and another verified the extracted data in full. We analyzed data using descriptive statistics and a thematic content analysis.

SETTING OR DATASET. We searched MEDLINE, Embase, PsycINFO, CINAHL, and Web of Science databases.

POPULATION AND INTERVENTION. We included any person or organization involved in permission to contact approaches, in any healthcare settings.

OUTCOME MEASURES. Any outcome related to the impact, benefits, risks, barriers, and facilitators of permission to contact approaches.

RESULTS. Our searches yielded 9364 publications of which 58 were retained for analysis. Permission to contact can take many forms (single permission, EMR-embedded permission, or a contact list) and is generally well accepted by patients. It has several benefits, such as facilitating recruitment, and fostering

patient engagement and autonomy principles. Risks include sampling bias as well as confidentiality and security concerns. Various factors may facilitate or hinder the implementation of this approach, including finding the right timing and setting to obtain patients' permission, or managing issues of data accuracy and completeness.

CONCLUSIONS. Permission to contact is a promising approach to address recruitment challenges in health research studies. In order to anticipate these, a well-planned implementation strategy involving key knowledge users is encouraged.