

NAPCRG 52nd Annual Meeting — Abstracts of Completed Research 2024.

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Title

Naming Disinclusion: The absence of marginalized populations in health research

Priority 1 (Research Category)

Health Care Disparities

Presenters

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Abstract

Context:

The underrepresentation of marginalized populations in epidemiology can jeopardize the validity of research, leading to selection biases, missing data, and undermining generalizability. When marginalized populations are absent from health research, their health needs remain obscured. This can imperil their health and social standing, alienating them from health research and othering them in the scientific narrative. This can further exclude marginalized groups from medicine and research. Still, the inequitable underrepresentation of marginalized groups goes unnamed in the epidemiological lexicon and is insufficiently characterized by existing methodological concepts. Methods, concepts, and the notion of epidemiological rigour must therefore evolve so that the everyday practice of epidemiology can advance science that is both rigorous and equitably advances the health of all.

Objective:

We aim to promote more inclusive and equitable research methods by advancing a new concept in health research and epidemiology to refer to the absence and invisibility of marginalized populations in health research.

Study design:

Theoretical and philosophical inquiry. We reviewed and appraised existing concepts in health research methods, characterized gaps, and proposed alternative theory and conceptualizations to advance our stated objective.

Setting or Dataset:

The study pertains to the field of health research methods and epidemiology, with a particular relevance for community-based research, primary care, and public health.

Results:

We propose a new methodological concept called 'disinclusion' to capture the inequitable absence or invisibility of a group in epidemiological data and health research. We define disinclusion and distinguish it from related methodological concepts such as underrepresentation, exclusion, missing data, and generalizability. We describe pervasive processes of disinclusion and provide examples of groups who are frequently affected by disinclusion. We propose to consider disinclusion in study design, reporting, and critical appraisal to illuminate the routine epidemiological practices that compound health inequities.

Conclusions:

Disinclusion is a new methodological concept in health research methods and epidemiology. Considering and addressing disinclusion alongside other methodological concerns and sources of bias can help make health research more equitable, inclusive, and rigorous.

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