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“You Cannot Collect Data Using Your Own Resources And Put It On Open Access”: Perspectives From Africa About Public Health Data-Sharing

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Data-sharing is a desired default in the field of public health and a source of much ethical deliberation. Sharing data potentially contributes the largest, most efficient source of scientific data, but is fraught with contextual challenges which make stakeholders, particularly those in under-resourced contexts hesitant or slow to share. Relatively little empirical research has engaged stakeholders in discussing the issue. This study sought to explore relevant experiences, contextual, and subjective explanations around the topic to provide a rich and detailed presentation of what it means to different stakeholders and contexts to share data and how that can guide practice and ethical guidance. A qualitative design involving interviews was undertaken with professionals working in public health institutions endowed with data (HDSS), ethics committees, and advisory agencies which help shape health research in Africa. A descriptive form of thematic analysis was used to summarize results into six key themes: (1) The role of HDSSs in research using public health data and data-sharing; (2) Ownership and funding are critical factors influencing data-sharing; (3) Other factors discourage data-sharing; (4) Promoting and sustaining data-sharing; (5) Ethical guidance structures; and (6) Establishing effective guidance. The themes reveal factors regarding the willingness or not to share and an intricate ethical system that current discourse could reflect. Many of the concerns resonate with the literature, but a whole other gamut of people and process issues; commitments, investments, careers, and the right ethical guidance are needed to realize a sustainable goal of reaching ‘share’ as a default.
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