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Co-designing a Governance Framework for Routine Linkage of Clinical Registries: The CROSS-Link Project

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Australia is home to over 120 clinical registries working to improve patient outcomes through quality assurance reporting and/or research. Although clinical registries can expand the utility of their data through data linkage with administrative data collections, this is most commonly done on a one-off basis, without clear guidance on cross-jurisdictional constraints, which inflates both completion times and costs. Motivated by reports from Australian data linkage units that numbers of such labour-intensive data linkage requests were increasing, the Population Health Research Network launched the Clinical Registries Optimised and Streamlined Solution for Data Linkage (CROSS-Link) project. CROSS-Link aimed to collaboratively design a governance framework to enable routine updating of clinical registries with administrative data while meeting required legal, ethical, and privacy standards. Three work

programs were completed to provide the knowledge needed to achieve this aim: 1) A governance program investigated the ways in which legal and ethical frameworks across Australian jurisdictions enabled or restricted routine linkage with clinical quality registries. 2) A consumer involvement program conducted focus groups and interviews to understand the concerns, hopes, and priorities around data linkage of individuals in a clinical registry, carers, and families. 3) A technical advice program designed feasible data flows to support routine linkage, surveying the governance arrangements and technical requirements of clinical registries affecting their capacity to undertake data linkage. Findings from these work programs informed a co-design process involving experts from around the country, and placing consumer priorities at its core, to design a governance framework and supporting guidance materials.

