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Building confidence in the secondary use of general practice data: the GP Data project

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With over 80% of Australians visiting a general practitioner (GP) annually, general practice records offer substantial research potential. However, community and GP concerns, particularly about privacy and data misuse, have constrained their secondary use. The GP Data Project explored how general practice data can be ethically and legally shared for research in Australia while maintaining public trust. This five-year project had multiple components: community focus groups; a national community survey; two community juries; a legal and policy analysis; qualitative interviews with GPs, practice managers, regulators and policy makers, and Human Research Ethics Committee chairs; and a Delphi survey of GPs. The final component – a Stakeholder Roundtable Conference – synthesised empirical evidence and co-designed actionable policy recommendations. Across all components of the project, we

found conditional support for sharing general practice data, contingent on transparency, robust safeguards, and inclusive governance. Most stakeholder groups preferred opt-out consent over other approaches to consent, reflecting the sensitivity of general practice data, and the importance of maintaining trust between GPs and their patients. Our legal analysis revealed misalignment between privacy legislation and the equitable duty of confidence, highlighting the need for statutory reform. The roundtable used collaborative methodologies to build a framework that integrated ethical principles, legal clarity, and practical feasibility. The Australian GP Data Project has used inclusive and robust methods to develop a framework that reconciles privacy obligations with research needs, addressing persistent consent challenges and enabling secure, socially licenced use of general practice data.

