

Table 1. Characteristics of 9 included studies addressing participant attitudes towards data sharing

Study (year)	Country of Research	Study design	Participant characteristics	Aim	Key Themes of study	Quality Appraisal
Asai et al (2002)	Japan	Focus group interviews and brief demographic questionnaire.	Lay participants aged 35-55, married with children, with experience or relatives experience of inpatient care during the preceding 5 years. No close family members who were health care professionals.	To explore laypersons' attitudes toward the use of archived (existing) materials such as medical records and biological samples (and to compare them with the attitudes of physicians who are involved in medical research).	<ul style="list-style-type: none"> • Types of consent • Prerequisites for sharing • Benefits to public • Ownership of medical records • Trust in researchers 	CASP: 8/10 'yes' answers
Cheah et al (2015)	Thailand	Focus group with 7, interview with 1. Topic guides taken from a template developed collaboratively with partners from other sites.	Community members acting as 'community representatives', affiliated with Shoklo Malaria Research Unit where they had been hired as temporary community engagement staff.	To understand attitudes and experiences of relevant stakeholders about what constitutes good data sharing practice.	<ul style="list-style-type: none"> • Benefits of sharing • Concerns and harms • Suggestions for best practice 	CASP: 9/10 'yes' answers
Hate et al (2015)	India	Focus groups conducted at outreach centres. Attended by field workers as a reassuring presence. Series of scenarios presented that drew on previous contributions to research.	(Employees or) participants in research conducted by SNEHA. Participants were familiar with the organisation and its work. 20 female community members.	To identify features of ethical data sharing practice in the context of research involving women and children in informal settlements. Specific objectives were to examine stakeholders' understandings, concerns, and hopes about what would happen to data and their views on what might constitute good data sharing practice; to identify models of data sharing and governance currently in use; to examine contextual considerations affecting data sharing processes; to identify perceived principles of good practice in data sharing; and to consider suitable	<ul style="list-style-type: none"> • Benefits of data sharing • Harms of sharing • Barriers to sharing • Obligations and responsibilities • Prerequisites for data sharing • Governance and policy • Broad, middle and explicit consent. 	CASP: 10/10 'yes' answers

				methods of developing appropriate data sharing processes.		
Jao et al (2015)	Kenya	Small group discussions (5-6 people) lasting 3-4 hours. After discussion groups, 3-4 individuals were chosen (reflecting differences in attitude and gender) for interviews lasting 30-45 mins.	A range of stakeholders including 30 community members including assistant chiefs (6) and community representatives (24) with relatively low research experience.	A consultation on data sharing, mapping the views and values of diverse stakeholders in a large international research program, the Kenya Medical Research Institute (KEMRI). This paper focuses on views on 'fair processes' in data sharing.	<ul style="list-style-type: none"> • Types of consent • Informed consent process • Community engagement • Feedback on data sharing process • Oversight for decisions on access to data • Perceived benefits and challenges 	CASP: 10/10 'yes' answers
Jao et al (2015)	Kenya	Small group discussions (4-6 people) with case study and vignette. Emerging findings noted and used to prompt discussion. After discussion groups, 3-4 individuals were chosen (reflecting differences in attitude and gender) for interviews lasting 30-45 mins	Community representatives- 'typical' community members selected by and from local villages at public meetings to support interactivity for a 3 year period, and participate in annual workshops on research related topics.	To report research stakeholders perceptions of benefits and challenges in sharing data and the emerging importance of trust at individual and institutional levels.	<ul style="list-style-type: none"> • Importance of data sharing • Challenges and concerns for primary communities • Risks of harms • Fairness to the primary community • Challenges and harms for originating researchers • Misuse of data • Does it matter who's asking? 	CASP: 10/10 'yes' answers
Manhas et al (2015)	Canada	Semi structured interview guide used in focus	Maternal and paternal participants in two longitudinal pregnancy cohort	To explore parent perspectives about sharing their own, and their child's non-biological data.	<ul style="list-style-type: none"> • Altruism has limits • Participants have ongoing privacy concerns 	CASP: 10/10 'yes' answers

		groups and individual interviews. Recruitment, data collection and analysis continued until data saturation reached.	research studies. Purposive sampling to identify participants who were fathers and mothers, older and younger than 30, visible minorities and new immigrants.		<ul style="list-style-type: none"> Some participants believe that congruence in values between themselves and research/researchers is important 	
Manhas et al (2016)	Canada	Group and individual interviews	Maternal and paternal participants in two longitudinal pregnancy cohort research studies. Purposive sampling to identify participants who were fathers and mothers, older and younger than 30, visible minorities and new immigrants.	To examine parent preferences for sharing non-biological data, specifically in regards to the consent process.	<ul style="list-style-type: none"> Reciprocity: parents want reciprocity among participants, repositories and researchers regarding respect and trust. Accuracy: parents worry about the interrelationships between validity of the consent processes and secondary data use. 	CASP: 10/10 'yes' answers
Merson et al (2015)	Vietnam	Focus groups with participants and their families.	15 clinical research participants enrolled in observational or cohort studies from northern and southern, rural and urban centres.	To explore stakeholders' understanding, perceptions, experiences attitudes and concerns about sharing individual level clinical data.	<ul style="list-style-type: none"> Views about a novel initiative Views about acceptable sharing Trust consent 	CASP: 9/10 'yes' answers
Platt and Kardia (2015)	USA	119 item survey developed to evaluate predictors of trust in the health system, broadly defined as a web of relationships among health	447 members of the general public. 51.5% male, aged 18-65 (most aged 26-34). White (76.1%) Black (7.16%), Asian (8.05%), Hispanic (4.70%), Other (3.13%). Most were college or some college educated. 62% non-home owners. Self-rated health,	To identify characteristics of the general public that predict trust in a health system that includes researchers, health care providers, insurance companies and public health departments. RE Data Sharing in particular: 'our study looks to see whether knowledge impacts trust in data sharing and if so, whether or not it increases support'.	<ul style="list-style-type: none"> Knowledge of health information sharing Privacy concerns Expectations of benefit 	Best Bets Survey Checklist Quality Assessment Tool: Paper rating 7/10

		care providers, departments of health, insurance systems and researchers. Included 6 trust characteristics included in conceptual model as well as additional questions about trust in specific institutions.	excellent 18%, very good 40% good 29%, fair 11%, poor 1.6%			
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