

Table 4. Characteristics of Included Studies

Citation, Year, Country	Design/Method	Sample Information
Allen et al., 2011, Australia	Qualitative; semi-structured interviews	Healthy cohort of participants (n=24) in actual biobank
Barr, 2006, England	Qualitative; semi-structured interviews	Female patients (n=43) who donated to actual biobank
Beskow et al., 2016, U.S.	National online survey; randomized experiment	Hypothetical decision-makers (n=1916)
Beskow et al., 2008, U.S.	Qualitative; cognitive interviews	Hypothetical decision-makers (n=40)
Bickmore et al., 2009, U.S.	Randomized experiment using BICEP	Hypothetical decision-makers (n=29)
Busby, 2004, England	Qualitative/ interviews	Donors (n=27) to an actual genetic research project
Cervo et al., 2013, Italy	Descriptive; self- administered questionnaire	Patients (n=430) enrolled in actual biobank studies
Dixon-Woods et al., 2007, England	Qualitative; semi-structured interviews	Healthy volunteers (n=29) in an actual genetic study
Ducournau et al., 2009, France	Qualitative; observation & interviews	Men (n=60) offered a check-up & asked to participate in actual biobank
Hoeyer, 2003, Sweden	Qualitative; observation & interviews	Donors and refusers (n=29) recruited as participants in actual program offering check -ups
Joseph et al., 2008, U.S.	Survey; verbally administered, in-person	Female donors and refusers (n=93) to an actual biobank

Citation, Year, Country	Design/Method	Sample Information
Klima et al., 2014, U.S.	Survey; mailed, self- administered QuIC	Parents (n=252) who actually enrolled their children to participate in congenital cardiovascular malformation research that included biobanking
Mahnke et al., 2014, U.S.	Proof of concept study testing hypothetical computer-based consent	Community members (n=9) representative of potential biobank participants
Mancini et al., 2011, France	Mailed, self-administered, 12- page questionnaire	Patients (n=574) treated for cancer and actually asked to donate tumor samples for research
Marshall et al., 2006, Nigeria & U.S.	Qualitative & Quantitative; survey & interviews	Clinic patients and controls (n=655) actually enrolled in genetic hypertension study in Nigeria & U.S.
Marshall et al., 2014, Nigeria	Qualitative & Quantitative; survey & interviews	Female cases and controls (n=215) enrolled in an actual genetic epidemiological study on breast cancer
Matsui et al., 2012, Japan	Intervention study; add-on cluster, randomized controlled trial	Patients (n=336) actually consenting to genetic cohort study
Matsui et al., 2007, Japan	Descriptive study of intervention using a 2- question, in-person questionnaire	Patients (n=2192) being asked to participate in actual genetic cohort study

Citation, Year, Country	Design/Method	Sample Information
McCarty et al., 2015, U.S.	Randomized controlled trial; mailed, self-administered QuIC	Men with prostate cancer (n=71) willing to enroll in actual biobank
McCarty et al., 2008, U.S.	Qualitative; focus group (Focus Group Series 3)	Potentially eligible biobank subjects (n=21)
McCarty et al., 2007, U.S.	Mailed, self-administered QuIC	Random sample of actual biobank participants (n=924)
McCaughey et al., 2016, Australia	Retrospective survey: mailed/ e-mailed, 35-item questionnaire with 14 questions re: understanding	Patients and controls (n=141) who actually donated a biospecimen for ophthalmic research
McGraw et al., 2012, U.S.	Qualitative; cognitive interviews evaluating written versus video informed consent	Patients and community members (n=43) making hypothetical biobanking decision
Merz & Sankar, 1998, U.S.	Descriptive survey	Prospective jurors (n=99) making hypothetical decision
Moutel et al., 2001, France	Self-administered questionnaire	Patients (n=51) enrolled in actual biobanking study
Ormond et al., 2009, U.S.	Qualitative & Quantitative; interviews & QuIC	Actual biobank participants (n=200)
Panoyan et al., 2008, U.S.	Survey; self-administered questionnaire	Participants (n=151) in actual genetic study
Petersen et al., 2014 Belgium, Germany, & UK	Self-administered questionnaire	Female breast cancer patients in Belgium (n=152), Germany (n=122), and UK (n=122)
Rahm et al., 2013, U.S.	Self-administered questionnaire	Donors and refusers (n=203) to hypothetical biobank

Citation, Year, Country	Design/Method	Sample Information
Robinson et al., 2013, U.S.	Randomized trial; interview & questionnaire	Individuals (n=229) recruited into actual studies
Roessler et al., 2015, U.S.	14 question quiz or semi-structured interview (self-rated understanding only)	Research volunteers and patients (n=480) being asked to enroll in actual biobank
Shelton, et al., 2015, U.S.	Intervention study; experimental post-test only; in person, self-administered questionnaire	Visitors (n=134) in waiting rooms; hypothetical decision to donate biospecimen of family member
Simon et al., 2015, U.S.	2 x2 experimental design; prospective randomized study /online survey, QuIC	Patients (n=200) approached for enrollment into an actual biobank
Toccaceli et al., 2009, Italy	Mailed, self-administered survey	Participants (n=99) recruited from a twin registry and radio ads for actual genetic study

BICEP=Brief Informed Consent Evaluation Protocol instrument; QuIC= Quality of Informed Consent instrument