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A systematic review of public perception and attitudes toward informed consent in biobanking.

Rachel McCarter, Jacqueline James, Hazel Fisher, Ethna McFerran, Julie McCarroll, Joanne Reid, Claire Lewis

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Review question

Main question:

1) What are public* perceptions and attitudes toward informed consent in biobanking?

Secondary Questions:

1) Do the public have any preferred methods or approach to consent for biobanking?

2) Is there sufficient evidence to inform best practice in biobank consent? If not, what areas need further research?

*Defined as members of the public, patients or research participants.

Searches

Electronic searches will be conducted of four databases: Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medical Literature Analysis and Retrieval System Online (MEDLINE), Excerpta Medica dataBASE (EMBASE) and Web of Science. The search strategy will be optimised by the Subject Librarian for Medicine, Dentistry & Biomedical Sciences, Queen's University Belfast and include keywords and synonyms of biobanking, informed consent, patient/participant/public and perception/understanding/view/comprehension/opinion / attitudes as detailed in Table 1. The MEDLINE search strategy is outlined below, and this will be adapted for the other databases as appropriate.

A search of PROSPERO has already been conducted to ensure no duplication of a review and to check that one had not been registered previously.

Searching other resources

We will examine the reference lists from reviewed articles for any additional studies. We will also search trial registers including Current Controlled Trials, National Cancer Institute and Clinical Trials.gov. Hand searching will include an examination of published abstracts from relevant conferences such as the International Society for Biological and Environmental Repositories (ISBER) and European, Middle Eastern & African Society for Biopreservation and Biobanking (ESBB).

The primary author will contact the corresponding study author of any relevant abstracts requesting a full publication if available. Only articles available in English will be included in this review and initially, there will be no restrictions on the year of publication. Studies published between the start date of each database e.g. 1946 for MEDLINE and the date the searches are run will be sought. Prior to the final analysis, the searches will be re-run and additional, recently published articles will be included.

Types of study to be included

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We will include all study types for this review that include original empirical data (qualitative or quantitative) including but not limited to surveys, focus groups, randomised control trials (RCTs) and non-randomised trials. Studies will be included if participants have been asked about or have involved in the biobank consent process. Excluded studies will be literature reviews, editorials, opinion pieces, theoretical papers, essays and newspaper articles. Clinical, diagnostic or therapeutic (non-research) studies which are about the donation of biospecimens will be excluded. Studies published only as conference abstracts or posters will be excluded. Studies not in English will also be excluded, as there is no budget to facilitate translation.

Condition or domain being studied

We will evaluate and report public/participants' perceptions/understanding of information for informed biobank consent (i.e. donating biological samples and data to a research biobank).

Participants/population

Inclusion: Adults (public, patients or biobank participants) who are able and willing to consent for donation of their biospecimens and data for research. To include those individuals who have or have not consented to biobanking.

Exclusion: Younger than 16 years.

Intervention(s), exposure(s)

The intervention/exposure to be reviewed is the informed consent process in biobanking. There is much debate within the biobanking literature on different approaches to consent, particularly whether biobanks should adopt a 'broad' model of consent where donors consent for future, unspecified research; or whether they adopt a 'narrow' model where donors are asked to consent for a specified study and are re-consented for any further use of their samples and data. There is a timely need to undertake a high quality, systematic review of biobank consent literature to identify the best, evidence-based approach to consent in biobanking.

Comparator(s)/control

Not applicable.

Context

Informed consent process in biobanking for the public or participants, and their preferred methods to consent for biobanking.

Main outcome(s)

The main outcome measure will be public and participants' perception and attitudes of the informed consent process for biobanking.

Timing and effect measures

Not applicable.

Additional outcome(s)

Are there any preferred methods/approaches that the public or participants have toward consent for biobanking? Is there sufficient evidence to inform best practice?

Timing and effect measures

Not applicable.

Data extraction (selection and coding)

All titles and abstracts retrieved from electronic searches will be downloaded to a reference management database such as Endnote. After duplicates are removed, the remaining citations will be checked for eligibility by CL and RVM. Full-text articles that cannot be excluded based on information presented in the title and abstract will be obtained for a full review. Any disagreements on eligibility between CL and RVM will be resolved through discussion with the review team until a consensus is reached. If the review authors require any additional information to determine eligibility, the primary author will contact the study authors directly. Clear reasons for exclusion will be documented for those studies that do not meet eligibility criteria.

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Data from eligible studies will be extracted independently by two reviewers (CL and RVM) using a standard data extraction form. This form will be piloted to ensure the review authors are retrieving similar results. The data extraction form will include details of the study methodology, study setting, participant characteristics, intervention(s), outcomes, the number enrolled in intervention/control, and risk of bias. When complete, all data will be presented in tabular form and categorised in accordance with the type of intervention.

Risk of bias (quality) assessment

All studies that have met the inclusion criteria will be assessed independently for quality by at least two review authors (CL and RVM). Differences will be resolved by discussion with a third review author (JR).

Included RCTs will be assessed using the Risk of bias guidelines specified in the Cochrane Handbook 5.0.2 (2009). The Newcastle – Ottawa Scale (NOS) will be used to assess the quality of non-randomised studies, including cohort and case-control studies. For qualitative studies, the Standards for Reporting Qualitative Research (SRQR) will be used to assess quality.

Strategy for data synthesis

For qualitative data, we will use thematic synthesis (Thomas and Harden, 2008). This will allow us to develop analytical themes through a descriptive synthesis, to offer conclusions relevant to the review question (Ring et al, 2010). If possible, we will undertake a quantitative synthesis of the quantitative data; however, this will be dependent on the quality and the heterogeneity of such studies. Quantitative data may, therefore be reported descriptively.

Analysis of subgroups or subsets

Is there a difference in perceptions and attitudes between those who have already consented for biobanking versus those who have not?

Contact details for further information

Dr Claire Lewis
claire.lewis@qub.ac.uk

Organisational affiliation of the review

Northern Ireland Biobank; Health Sciences Building, Queen's University Belfast, 97 Lisburn Road, Belfast, BT9 7BL
<http://www.niobiobank.org/>

Review team members and their organisational affiliations

Dr Rachel McCarter. Northern Ireland Biobank; Health Sciences Building, Queen's University Belfast, UK
Dr Jacqueline James. Northern Ireland Biobank; Health Sciences Building, Queen's University Belfast, UK
Mrs Hazel Fisher. Biobank PPI rep/Northern Ireland Cancer Research Consumer Forum (NICRCF), Belfast, UK
Dr Ethna McFerran. Centre for Cancer Research and Cell Biology, Queen's University Belfast, UK
Dr Julie McCarroll. HSC Public Health Agency, R&D Division
Professor Joanne Reid. School of Nursing and Midwifery, Queen's University Belfast, UK
Dr Claire Lewis. Northern Ireland Biobank; Health Sciences Building, Queen's University Belfast, UK

Type and method of review

Systematic review

Anticipated or actual start date

01 August 2019

Anticipated completion date

14 October 2019

Funding sources/sponsors

This review received funding from Friends of the Cancer Centre and the HSC Public Health Agency.

Conflicts of interest

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No conflict of interest has been declared by the authors.
None known

Language

English

Country

Northern Ireland

Stage of review

Review Ongoing

Subject index terms status

Subject indexing assigned by CRD

Subject index terms

Attitude; Biological Specimen Banks; Humans; Informed Consent; Perception

Date of registration in PROSPERO

26 July 2019

Date of publication of this version

05 August 2019

Revision note for this version

Dr Claire Lewis has been now added into the review team members, as she is the corresponding author.

Details of any existing review of the same topic by the same authors**Stage of review at time of this submission**

Stage	Started	Completed
Preliminary searches	Yes	No
Piloting of the study selection process	No	No
Formal screening of search results against eligibility criteria	No	No
Data extraction	No	No
Risk of bias (quality) assessment	No	No
Data analysis	No	No

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Versions

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