

Northumbria Research Link

Citation: Menezes, Ritesh G., Vears, Danya F., Minion, Joel T., Roberts, Stephanie J., Cummings, James, Machirori, Mavis, Blell, Mwenza, Budin-Ljøsne, Isabelle, Cowley, Lorraine, Dyke, Stephanie O. M., Gaff, Clara, Green, Robert, Hall, Alison, Johns, Amber L., Knoppers, Bartha M., Mulrine, Stephanie, Patch, Christine, Winkler, Eva and Murtagh, Madeleine J. (2021) Return of individual research results from genomic research: A systematic review of stakeholder perspectives. PLoS ONE, 16 (11). e0258646. ISSN 1932-6203

Published by: Public Library of Science

URL: <https://doi.org/10.1371/journal.pone.0258646>
<<https://doi.org/10.1371/journal.pone.0258646>>

This version was downloaded from Northumbria Research Link:
<http://nrl.northumbria.ac.uk/id/eprint/47672/>

Northumbria University has developed Northumbria Research Link (NRL) to enable users to access the University's research output. Copyright © and moral rights for items on NRL are retained by the individual author(s) and/or other copyright owners. Single copies of full items can be reproduced, displayed or performed, and given to third parties in any format or medium for personal research or study, educational, or not-for-profit purposes without prior permission or charge, provided the authors, title and full bibliographic details are given, as well as a hyperlink and/or URL to the original metadata page. The content must not be changed in any way. Full items must not be sold commercially in any format or medium without formal permission of the copyright holder. The full policy is available online: <http://nrl.northumbria.ac.uk/policies.html>

This document may differ from the final, published version of the research and has been made available online in accordance with publisher policies. To read and/or cite from the published version of the research, please visit the publisher's website (a subscription may be required.)

Study Overview

Your name:	
Date (DD MM YYYY):	

Alert(s) to Review Team leads:		Free text space to communicate important information to Review Team leads (e.g. paper does not appear to fit review criteria; PDF is incorrect version of paper).
---------------------------------------	--	---

Study aims:		Cut-and-paste aim of study directly from paper (or summarise if simpler).
Year(s) of data collection:		Put questions marks after years if uncertain/unclear. Use 'Not stated' if information not provided.

Type of research:	Drop down menu	Quantitative Qualitative Mixed methods
Specific method(s):	Drop down menu	Survey (including questionnaires) Interviews Focus groups Survey + Interviews Survey + Focus groups Interviews + Focus groups Other (please state)
Setting(s):		Briefly describe setting(s) where data were collected (e.g. online survey; telephone survey; face-to-face telephone interviews; focus groups in communities).

Format:	Drop down menu	Return of existing data / Direct experience Return of hypothetical data / Hypothetical scenario(s) Unclear / Not stated Other (please specify)
----------------	----------------	---

Country:		Indicate specific country. If multinational, indicate all countries involved. If necessary, write 'Not stated' and indicate most probable country/ies.
-----------------	--	--

Stakeholders

Stakeholders represented:		Describe who participated in study. Include details if provided (e.g. genetic counsellors; general public; family members of deceased men who had participated in study to identify genetic contributions to early-onset prostate cancer related to BRCA2).
Inclusion / exclusion criteria:		Provide details about who was and want not invited in study. Use 'Not stated' as necessary.
Stakeholder characteristics:		Describe stakeholders, especially if not White, middle class, educated and from higher income Western country/ies.
Age group(s):	Drop down menu	Adults (≥age 17) Children (<age 18) Adults + Children Other (please state)
Sample size:		Indicate as n=x. Provide breakdown where appropriate (e.g. Survey n=145 + Interviews n=14). Use cell on right for additional information as necessary.
Sampling procedure:		Indicate how participants were sampled. Differentiate between qualitative and quantitative methods as necessary.
Recruitment method:		Describe all methods used to contact participants for recruitment into study. Differentiate between qualitative and quantitative study arms as necessary.

Quantitative Results

Method of analysis:

Note any particular method of analysis used to frame study and analyse data. Use 'Unclear / Not stated' as necessary.

Key findings:

Identify key findings related to research question, "What are stakeholders' views and experiences regarding return of individual results from genomic research?".
Cut-and-paste from paper where possible.

Author explanations:

How do authors explain their findings? Cut-and-paste from paper as necessary.
Use 'Not stated' as necessary.

Qualitative Results

Method of analysis:

Note any theoretical framework or method of analysis used to frame study and analyse data (e.g. thematic analysis, interpretive phenomenological analysis). Use 'Unclear / Not stated' plus details as necessary.

Key findings:

Identify key findings related to research question, "What are stakeholders' views and experiences regarding return of individual results from genomic research?". Cut-and-paste from paper where possible.

Author explanations:

How do authors explain their findings? Cut-and-paste from paper as necessary. Use 'Not stated' as necessary.

Conclusions

Conclusions:

What main conclusions are drawn? Cut-and-paste from paper where possible.

Recommendations / Implications:

Note any recommendations or implications for practice put forward by authors. Cut-and-paste from paper where possible.

Study strengths:

Any strengths identified by authors or by you as reviewer (please distinguish yours from theirs). Cut-and-paste from paper where possible.

Study limitations:

Any limitations identified by authors or by you as reviewer (please distinguish yours from theirs). Cut-and-paste from paper where possible.

Before you go...

Reviewer's notes / comments:

Space for any final thoughts or for feedback to Review Team leads about this paper in particular or review process in general.

References to follow-up:

Please cut-and-paste any reference(s) from paper under review or elsewhere that meet study inclusion criteria. Complete list of papers identified for inclusion in review is in OneDrive folder alongside PDFs.