BMJ Open

Understanding the reasons for declining to participate in cancer genetics and genomic studies in the USA: a scoping review protocol

Joel Sanchez Mendez ,[1] Jessica Sanchez ,[2] Chenya Zhao,[1] Vernon Shane Pankratz,[2] Andrew L Sussman,[2] Ursa Brown-Glaberman,[2] Stephanie Cargill ,[3] Shiraz I Mishra,[2] Mariana C Stern [1,4]

To cite: Sanchez Mendez J, Sanchez J, Zhao C, *et al*. Understanding the reasons for declining to participate in cancer genetics and genomic studies in the USA: a scoping review protocol. *BMJ Open* 2025;**15**:e093998. doi:10.1136/bmjopen-2024-093998

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (https://doi.org/10.1136/bmjopen-2024-093998).

Received 21 September 2024
Accepted 20 March 2025

[1]Population and Public Health Sciences, University of Southern California, Los Angeles, California, USA
[2]The University of New Mexico Comprehensive Cancer Center, Albuquerque, New Mexico, USA
[3]Albany Medical College, Albany, New York, USA
[4]Norris Comprehensive Cancer Center, Keck School of Medicine, University of Southern California, Los Angeles, California, USA

Correspondence to
Dr Mariana C Stern; marianas@usc.edu and
Dr Shiraz I Mishra; smishra@unm.edu

ABSTRACT

Introduction Cancer is the second leading cause of death in the USA. Cancer genetics and genomic studies have improved our understanding of risk, onset and progression. However, disparities by race and ethnicity have resulted in a lack of representation for minorities in these studies, contributing to unequal reductions in the cancer burden across populations. Moreover, the reasons why some individuals decline to participate in cancer genetics and/or genomic studies across diverse populations remain unclear. This review will summarise the main reasons (concerns) associated with declining to participate in cancer genetics and/or genomic studies for individuals with a history of cancer living in the USA and Puerto Rico (PR), considering race and ethnicity.

Methods and analysis We will follow the methodology presented by the Joanna Briggs Institute and the Preferred Reporting Items for Systematic Reviews Statement extended to Scoping Reviews to guide manuscript generation. A standardised search strategy developed in collaboration with a health sciences librarian will be deployed in Medline (PubMed), Embase (Ovid) and Scopus from database inception till present. The search strategy consists of three concepts: (1) cancer; (2) genetics and genomic research; (3) declination to participate in research studies. Title and abstract screening, followed by full-text review, will be conducted by independent reviewers to determine study inclusion. Only the peer-reviewed literature in English, conducted in the USA and PR will be considered. Findings will be presented as a numerical summary, graphical presentation and narrative review of the literature.

Ethics and dissemination Ethical review is not required for scoping reviews. This review aims to facilitate the development of targeted strategies to increase participation in cancer genetics and/or genomic studies across diverse populations. Results will be disseminated through a peer-reviewed publication and conference presentations. The protocol is registered in the Open Science Framework (www.osf.io).

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ This scoping review will follow the guidelines provided by the Joanna Briggs Institute and the Preferred Reporting Items for Systematic Reviews Statement extended to Scoping Reviews to enhance the scientific rigour.
⇒ The study is conducted by a multidisciplinary team of researchers that collaborate across the National Cancer Institute Moonshot Initiative and Participant Engagement and Cancer Genome Sequencing Network comprising five comprehensive cancer centres with topic expertise.
⇒ Although no grey literature will be included in the review, an effort will be made to identify peer-reviewed publications derived from abstracts and symposia articles to consider for inclusion.

INTRODUCTION

Cancer is the second leading cause of death in the USA with 2 001 140 new cancer cases and 611 720 cancer deaths projected to occur in 2024 alone.[1] Cancer is a heterogeneous disease. This heterogeneity comes as a result of the complex interplay between multiple risk factors, including environmental and genetic factors.[2] With the rapid development of genomic technologies over the past decades, genetic/genomic testing has become a common practice in clinical settings for identifying individuals at increased risk of inherited conditions as well as for identifying the most effective treatments.[3]

Genetic testing encompasses both germline and somatic testing. Germline genetic testing can enhance the understanding of the inheritance pattern of cancer and help manage the cancer risks.[4] Centers for Disease Control and Prevention suggests that individuals with a personal or family history of cancer should undergo genetic testing for hereditary cancers, such as breast and ovarian cancer among others, due to their significant genetic influence.[5] Genomic testing of the tumour can provide

information on the prognosis after a person is diagnosed with cancer, as well as help inform the most optimal cancer treatments, enabling personalised medicine in oncology and ultimately improve survival outcomes.[6] Genetic and genomic testing can be further categorised into clinical and research testing. Clinical testing primarily aims to guide diagnosis and treatment at the individual level, whereas research testing focuses on enhancing the global understanding of diseases within, between and across populations, without directly informing clinical decision-making.[7] However, current efforts tend to simultaneously offer clinical and research testing as part of the research study.

Advancements in identifying inherited and tumour genomic and genetic variation in precision oncology emphasise the need to increase the diversity among recruitment in cancer clinical trials. Racial and ethnic minority patients have been grossly under-represented in large-scale efforts to characterise the cancer genome.[8] Moreover, they have also been under-represented in precision oncology trials. For example, Aldrighetti *et al* analysed 197 precision oncology clinical trial studies and found that 47.2% had appropriate data on race and ethnicity while the remaining 52.8% did not have any information. The 93 studies with reported race and ethnicity data found that of the 5867 enrollees, 82.3% were non-Hispanic white, 10% were black, 4.1% were Asian, 3.4% were Hispanic and 0.3% were American Indian and Alaska Native.[9] As such, it is inadequate to generalise the presence or absence of biomarkers across populations based on the lack of diversity within cancer clinical trials.

Access to and utilisation of health services and specialty care, including genetic services, can improve health outcomes by increasing diagnosis rates among racial and ethnic minority groups, rural communities, people with disabilities and those with lower incomes.[10] A previous systematic review summarised that four primary motivators for pursuing clinical genomic testing were: interest in the tests' ability to predict cancer occurrence and recurrence risk, inform management decisions, benefit participants' families and provide participants with a better understanding of their cancer.[11] Unfortunately, Asian, black, Native American and Hispanic people are less likely to receive recommended clinical germline genetic testing.[12] This not only contributes to disparities in cancer care, but also lack of genetics and genomic research testing in diverse populations can prevent the understanding of health disparities, new discoveries in biology, more accurate matching of diverse patients with safe and effective treatments and an improved understanding of the impact of genetic variants in cancer risk.[13]

Despite information provided by genetics and genomic clinical and research testing, there is still some hesitancy among cancer patients to pursue this type of testing. Therefore, understanding the reasons why participants decline to enrol in genetics and/or genomic cancer studies is important. Moreover, these reasons vary across different regions and populations. A study found that the common reasons for declining genomic sequencing research testing include psychological impact, no interest in research activities, time commitment and privacy/discrimination.[14] Kurian *et al* found that only 6.8% patients pursued genetic testing after a cancer diagnosis in California and Georgia, with lower rates among Asian, black and Hispanic patients in comparison to Non-Hispanic white patients.[15] Another study by Smith-Uffen *et al* identified key barriers to genomic testing including concerns about cost, confidentiality, clinical utility and psychological harm.[11]

Given the heterogeneity of the results from studies that report on reasons for declining participation in genetics or genomic studies and the importance of understanding these reasons, a comprehensive synthesis of the sociodemographic characteristics and external factors associated with people who decline participation in these studies is necessary. Currently, only a few existing published syntheses have reported on the reasons why individuals choose to opt out of pursuing genetic and/or genomic testing in cancer research.[11 14 15] However, these studies have not considered racial and ethnic disparities and how these disparities could impact the decision to participate. Therefore, we propose to conduct a scoping review with the goal of identifying and synthesising the existing reasons for declining participation in cancer genetics and/or genomic testing, with special consideration of differences by race and ethnicity, as well as other sociodemographic factors.

Prior to the development of this scoping review protocol, we conducted a thorough search of Medline (Pubmed), Embase (Ovid), Scopus, PROSPERO, the Cochrane Database of Systematic Reviews, Open Science Framework and Joanna Briggs Institute (JBI) Evidence Syntheses. No previous registered, published or ongoing scoping reviews or systematic reviews on an equal or similar topic were identified.

The primary objective of the current review is to examine the reasons (concerns) why persons decline to participate in cancer genetics and genomic studies for individuals with a history of cancer living in the USA and Puerto Rico (PR). A secondary objective is to examine reasons why persons decline to participate in cancer genetics and/or genomic research considering race and ethnicity, age at diagnosis, gender, health insurance, nativity/immigration status, socioeconomic status, family history of cancer, cancer characteristics (ie, primary, metastatic; treatment status; cancer site; stage at diagnosis) and comorbidities. We aim to leverage the findings from this review to facilitate the development of target strategies to increase participation in cancer genetics and/or genomics research across diverse populations in the USA and PR.

METHODS AND ANALYSIS

Protocol design, registration and reporting

This scoping review will follow the guidelines generated by the JBI in the JBI Manual for Evidence Synthesis.[16]

This manual leverages the foundational methodology constructed by Arksey and O'Malley[17] with close consideration of the enhancement provided by Levac *et al*[18] and enables the generation of a review that will align with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) extension for Scoping Reviews.[19] In addition, this protocol was developed in accordance with the guidance and checklist published by Peters *et al*.[20] This scoping review protocol is registered online with the Open Science Framework (www.osf.io). We will start the proposed review on 3 March 2025 and complete it by 3 November 2025.

Review questions/objectives

Scoping review studies aim to rapidly map key concepts underpinning a specific research area/question.[21] In this review, we target three out of the four common reasons to undertake a scoping review as stated by Arksey and O'Malley. Specifically, we will: (1) examine the extent, range and nature of research activity in relation to reasons to decline to participate in cancer genetics and/or genomic cancer studies in the USA and PR; (2) summarise and disseminate our research findings to the broader scientific community and community representatives; (3) identify research gaps in the existing literature in relation to reasons to decline to participate in cancer genetics and/or genomic cancer research in the USA.

Motivated by these reasons to conduct this review, we propose the following research questions:

1. What are the reasons (concerns) expressed by persons with a history of cancer who decline to participate in cancer genetics and/or genomic studies in the USA and PR?
2. What are the sociodemographic attributes among individuals with a history of cancer who decline to participate in cancer genetics and/or genomic studies in the USA and PR?
3. What are the cancer-specific characteristics among persons with a history of cancer who decline to participate in cancer genetics and/or genomic studies in the USA and PR?
4. Are there different reasons (concerns) to decline to participate in cancer genetics and/or genomic studies by cancer type or race and ethnicity?

Eligibility/inclusion criteria

Types of participants/population

This scoping review will consider for inclusion the readily available peer-reviewed literature that reports on adults (≥18 years of age) with a current or previous diagnosis of cancer (either primary or metastatic) who have been approached in intrahospital or extrahospital settings to participate in cancer genetics and/or genomic studies in the USA and PR and have declined to partake in such studies. This criterion does not exclude participants based on how the diagnosis status was obtained (eg, clinical, histological, self-report). Moreover, we will not exclude the literature that reports on participants with a history of cancer diagnosis who have comorbidities or coexisting conditions (eg, pregnancy) (table 1).

Concept

In this study, we target literature that examines the reasons (concerns) why individuals with a prior cancer history decline to participate in cancer genetics and genomic studies in the USA and PR. This primary objective is decomposed into three concepts defined as follows:

1. *Cancer*: To describe cancer, we adhere to the recent definition demarcated by Brown *et al*, which defines cancer as a 'disease of uncontrolled proliferation

Table 1 Inclusion and exclusion criteria across phases of study selection for scoping review.

Selection phase	Inclusion criteria	Exclusion criteria
Title and abstract screening	1. Study is conducted in humans. 2. Study is conducted in the USA and/or Puerto Rico. 3. Study is focused on individuals with a positive history of cancer diagnosis. 4. There is a mention of genetics and/or genomics for cancer research.	1. Study is not a peer-reviewed publication. 2. There is no mention of genetic and/or genomic testing. 3. Study was not conducted in the USA or Puerto Rico. 4. Study is not reported in English. 5. Study does not include participants with a history of cancer diagnosis.
Full-text review	1. A genetic and/or genomic assay was performed in at least a subset of the study participants. 2. Reasons and/or concerns associated with the decision to decline to participate in a study are provided either with a numerical summary or narrative description. 3. Study reports sociodemographic characteristics of study participants. 4. Study reports clinical characteristics of study participants.	1. No information is provided on reasons and/or concerns associated with the decision to decline to participate. 2. The clinical and sociodemographic characteristics of the study participants are not described (ie, the population under study is not described). 3. The genetic and/or genomic assay that was used is not described. 4. No information on funding sources and conflicts of interest is provided.

by transformed cells subject to evolution by natural selection'.[22]

2. *Genetics and/or genomic studies*: The WHO defines 'genetics' as the study of hereditary patterns of inheritance among organisms with a focus on the specific gene structure and variations to form a clear picture of the potential for a condition. While 'genomics' is defined as the study of the genome and its actions; it refers to all the DNA contained in a cell including the nuclear and mitochondrial DNA.[23] Thus, genomics involves the analysis of the full DNA sequence of an organism, whereas genetics interrogates the functioning and composition of one or more genes. Therefore, for the purpose of this review, we define cancer genetics and/or genomic studies as the investigational efforts conducted in individuals with a history of a cancer diagnosis to elucidate the molecular elements that influence cancer presentation, progression and outcomes. This research leverages genetic and/or genomic testing technologies to inform the biological basis of different cancer types, develop targeted therapies and interventions, discover genomic biomarkers of drug response and resistance, provide targeted genetic counselling, and potentially guide clinical decision-making.[24]
3. *Declination/refusal to participate*: We operationally define a 'declination to participate' as the non-coerced negative from protocol-eligible subjects to partake in cancer genetics and/or genomic research studies at any capacity. Thus, a 'decliner' is defined as a potential participant that directly or indirectly (eg, through a family member) informed the study staff they were unwilling or unable to participate after being contacted for recruitment. The 'declination to participate' decision may occur before, during or shortly after informed consent, depending on the project's protocol, but will always take place before the person who declines to participate is subject to any study-related activities.[14]

Context

The context of this review will be settings with individuals with a positive history of cancer diagnosis residing either in the USA or in PR at the time they choose to not participate in a cancer genetics and/or genomic study. Thus, studies that did not perform a genetic and/or genomic test, or where no information is provided vis-à-vis a genetic and/or genomic assay will be excluded (table 1).

We acknowledge that the reasons for declining participation in cancer genetics and/or genomic studies may vary between clinical and research testing. In this review, both types of testing will be considered for inclusion, with notations added to distinguish the rationale behind the specific type of testing conducted when possible.

Information sources

This scoping review will consider all observational, interventional and review study designs including: analytical cross-sectional studies; prospective, retrospective, ambidirectional cohort studies; case-control studies and its variations according to methods of control sampling (ie, nested case-control study using risk-set sampling, case-cohort sampling and cumulative case-control study); randomised controlled trials; controlled clinical trials; qualitative studies; quantitative studies, mixed-methods studies; systematic reviews; meta-analyses; narrative reviews.

The databases to be searched will include Medline (PubMed), Embase (Ovid) and Scopus. Both Embase and Scopus cover the search of 'grey' literature (ie, conference abstracts, symposia articles, book chapters, etc). If abstracts or symposia articles are detected, an effort to identify peer-reviewed publications derived from these sources will be made. If none are available, the entries will not be included. Databases will be interrogated from inception to the present, with only the literature published in English considered for inclusion (table 1).

Search strategy

The search strategy was developed in collaboration with an expert health sciences librarian (Jennifer Dinalo) from the Keck School of Medicine at the University of Southern California. An initial search was conducted in Medline (PubMed) to identify relevant articles on the topic. Keywords were extracted from the titles, abstracts and manuscript body and were used in combination with the index terms to develop a full search strategy for Medline (PubMed) (online supplemental table 1). The proposed search strategy encompasses three main concepts: 'cancer', 'genetics and/or genomic studies' and 'declination/refusal to participate'. These concepts are decomposed into terms indexed in the National Library of Medicine, controlled vocabulary thesaurus (Medical Subject Headings (MeSH)) (https://www.ncbi.nlm.nih.gov/mesh/). This search strategy will be adapted to each information source. References cited in articles that met inclusion criteria will be reviewed to identify additional literature for inclusion and supplemented with hand searching. Following JBI recommendations,[16] a pilot test screening of eligible studies will be conducted by two independent reviewers. The search strategy will be updated accordingly.

Selection of sources of evidence

Identified records from all sources of evidence will be collated and uploaded into Covidence, an online screening and data extraction tool for systematic reviews (https://www.covidence.org). Duplicate records will be removed. A two-stage screening process will ensue to select studies for this review: (1) title and abstract screening and the retrieved literature of potentially eligible studies will be screened against inclusion and exclusion criteria and labelled as 'include', 'exclude' or 'uncertain'; (2) full-text review, we will extract full-text publications from studies labelled as 'include' or 'uncertain' to evaluate against the inclusion and exclusion criteria. All studies will be independently reviewed by at

least two reviewers, with conflicts resolved by a third independent reviewer. For the literature labelled as 'exclude' after full-text review is conducted, the reasons for exclusion will be documented.

Full-text publications from studies that meet the inclusion criteria will be imported into Zotero V.7.0.11 for citation management. The results of the selection process will be presented in the final scoping review as a PRISMA flow diagram.[25]

Critical appraisal of individual sources of evidence

Scoping reviews are not required to conduct an assessment of the methodological quality of the retrieved literature.[20] As the primary goal of this review is to examine the extent, range and nature of available evidence in our topic of interest, we have opted not to critically appraise the studies we will include.

Data charting process

Data will be extracted by two reviewers into Covidence following the fields specified in a standardised data extraction tool (online supplemental table 2). The tool will be piloted by three reviewers who will independently chart data from the first five studies, with adjustments made accordingly after a discussion among the team. Additionally, the data extraction tool may be iteratively updated to ensure that unforeseen data are usefully captured. Modifications made to the presented tool (online supplemental table 2) will be recorded and mentioned in the full scoping review manuscript.

We will extract information from the following categories: (1) publication details, (2) study characteristics, (3) study methods, (4) sociodemographics of study participants, (5) clinical characteristics of study participants and (6) study results. Specifically, the study results will focus on the following: participation rate, reasons for declining to participate, sociodemographic and clinical characteristics of decliners, and strategies to enhance participation, in cancer genetics and/or genomic studies.

Collating, summarising and reporting the results

Studies will be grouped by design into qualitative, mixed methods and quantitative research, with the latter further stratified into cross-sectional and longitudinal studies. Data will be summarised following this stratification, with results presented in three blocks of information by study type as follows: (1) studies that deployed qualitative and/or mixed methods, (2) studies that report on quantitative research efforts (stratified into cross-sectional and longitudinal) and (3) studies that were not initially conducted to evaluate reasons for declining to participate in cancer genetics and/or genomic studies but meet inclusion/exclusion criteria and report sufficient results to be included in the scoping review.

After grouping the included literature into these three categories, we will present the data using the following strategies:

Descriptive numerical summary

This includes the publication details, study characteristics and study methods as described in the data extraction tool (online supplemental table 2), namely, publication year, publication source, study design, study setting/location, study sponsor/funding source, sampling method, if an incentive for participation was offered, primary versus secondary data analysis, sequencing platform/technology used to obtain the genetic and/or genomic information, time commitment for participation in the study, study activities and method of recruitment.

Graphical presentation of the charted information

The reasons and factors associated with the decision to decline participation in cancer genetics and/or genomic research will be collected and presented in bar graphs. The x-axis will display the reasons and/or factors, while the y-axis will show the number of studies reporting on these reasons and factors. Results will be stratified according to the three blocks of information previously constructed. Efforts will also be made to stratify the results by sociodemographic or clinical characteristics of the populations under study (eg, sex, race and ethnicity, socioeconomic status, cancer type), if feasible.

Narrative review of the literature

Studies will be grouped thematically according to the reported reasons and factors associated with the decision to decline to participate in cancer genetics and/or genomic studies. For studies of qualitative nature, a narrative review of the findings will be provided, with similarities and differences in the different methodological efforts to increase participant accrual emphasised. In addition, clinical and sociodemographic characteristics of the study participants that cannot be quantitatively presented and that may be associated with study participation rates will be described in this section.

Conclusions for the full scoping review will be drawn from all these three strategies. This will enable the identification of predominant factors that may influence decision-making in cancer genetic and/or genomic research, potentially transforming them into actionable strategies to improve recruitment in future research efforts.

Patient and public involvement

No patient or public representatives were involved in the design, conduct, reporting or dissemination of this protocol.

ETHICS AND DISSEMINATION

Ethical review is not required for scoping reviews as only secondary data analyses from publicly available data are conducted. Results will be disseminated with a peer-reviewed publication and conference presentations.

Acknowledgements The authors wish to thank Jennifer Dinalo, Librarian Specialist at the University of Southern California, for her support in developing the search strategy and database selection.

Contributors Conceptualisation: MCS and SIM; design of the protocol, MCS, SIM, JSM, JS and SC; draft of the manuscript, JSM, JS, CZ, SIM, MCS, SC and ALS; review and final approval of the manuscript: JSM, JS, CZ, VSP, ALS, UBG, SC, SIM and MCS. Guarantor: MCS.

Funding This project was partially supported by award number P30CA014089 from the National Cancer Institute (NCI). JSM and MCS received support from awards U54CA233465 and U2CCA252971 from the NCI. JS, VSP, ALS, UBG and SIM received support from NCI award U2CCA252973. SC received support from NCI award 5U2CCA252981-02 with subaward WU-24-0047. The ideas and opinions expressed here are those of the author(s). The study funders had no role in the development, direction or writing of the manuscript.

Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, conduct, reporting or dissemination plans of this research.

Patient consent for publication Not applicable.

Provenance and peer review Not commissioned; externally peer reviewed.

ORCID iDs
Joel Sanchez Mendez http://orcid.org/0000-0001-5552-1020
Jessica Sanchez http://orcid.org/0009-0003-9431-3656
Stephanie Cargill http://orcid.org/0000-0002-1782-0481
Mariana C Stern http://orcid.org/0000-0001-9777-4683

REFERENCES

1 Siegel RL, Giaquinto AN, Jemal A. Cancer statistics, 2024. *CA Cancer J Clin* 2024;74:12–49.
2 Marahatta SB, Sharma N, Koju R, *et al*. Cancer: determinants and progression. *Nepal Med Coll J* 2005;7:65–71.
3 Hong Y-R, Yadav S, Wang R, *et al*. Genetic Testing for Cancer Risk and Perceived Importance of Genetic Information Among US Population by Race and Ethnicity: a Cross-sectional Study. *J Racial Ethn Health Disparities* 2024;11:382–94.
4 Cella D, Hughes C, Peterman A, *et al*. A brief assessment of concerns associated with genetic testing for cancer: the Multidimensional Impact of Cancer Risk Assessment (MICRA) questionnaire. *Health Psychol* 2002;21:564–72.
5 CDC. Testing for hereditary breast and ovarian cancer. hereditary breast and ovarian cancer. 2024. Available: https://www.cdc.gov/breast-ovarian-cancer-hereditary/testing/index.html [Accessed 21 Jul 2024].
6 Jackson SE, Chester JD. Personalised cancer medicine. *Int J Cancer* 2015;137:262–6.
7 Shevchenko Y, Bale S. Clinical Versus Research Sequencing. *Cold Spring Harb Perspect Med* 2016;6:a025809.
8 Spratt DE, Chan T, Waldron L, *et al*. Racial/Ethnic Disparities in Genomic Sequencing. *JAMA Oncol* 2016;2:1070–4.
9 Aldrighetti CM, Niemierko A, Van Allen EM, *et al*. Racial and ethnic disparities among participants in precision oncology clinical studies. *JCO* 2021;39:3014.
10 Khoury MJ, Bowen S, Dotson WD, *et al*. Health equity in the implementation of genomics and precision medicine: A public health imperative. *Genet Med* 2022;24:1630–9.
11 Smith-Uffen M, Bartley N, Davies G, *et al*. Motivations and barriers to pursue cancer genomic testing: A systematic review. *Patient Educ Couns* 2021;104:1325–34.
12 Liu YL, Maio A, Kemel Y, *et al*. Disparities in cancer genetics care by race/ethnicity among pan-cancer patients with pathogenic germline variants. *Cancer* 2022;128:3870–9.
13 Bentley AR, Callier S, Rotimi CN. Diversity and inclusion in genomic research: why the uneven progress? *J Community Genet* 2017;8:255–66.
14 Amendola LM, Robinson JO, Hart R, *et al*. Why Patients Decline Genomic Sequencing Studies: Experiences from the CSER Consortium. *J Genet Couns* 2018;27:1220–7.
15 Kurian AW, Abrahamse P, Furgal A, *et al*. Germline Genetic Testing After Cancer Diagnosis. *JAMA* 2023;330:43–51.
16 Aromataris Em, ed. JBI Manual for Evidence Synthesis - JBI Global Wiki, Available: https://synthesismanual.jbi.global [Accessed 19 May 2023].
17 Arksey H, O'Malley L. Scoping studies: towards a methodological framework. *Int J Soc Res Methodol* 2005;8:19–32.
18 Levac D, Colquhoun H, O'Brien KK. Scoping studies: advancing the methodology. *Implement Sci* 2010;5:69.
19 Tricco AC, Lillie E, Zarin W, *et al*. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Ann Intern Med* 2018;169:467–73.
20 Peters MDJ, Godfrey C, McInerney P, *et al*. Best practice guidance and reporting items for the development of scoping review protocols. *JBI Evid Synth* 2022;20:953–68.
21 Mays N, Roberts E, Popay J. Synthesising research evidence. In: *Studying the Organisation and Delivery of Health Services*. Routledge, 2001.
22 Brown JS, Amend SR, Austin RH, *et al*. Updating the Definition of Cancer. *Mol Cancer Res* 2023;21:1142–7.
23 WHO. Genetics versus genomics. 2004. Available: https://web.archive.org/web/20040630170807/http://www.who.int/genomics/geneticsVSgenomics/en/ [Accessed 17 Jul 2024].
24 Berger MF, Mardis ER. The emerging clinical relevance of genomics in cancer medicine. *Nat Rev Clin Oncol* 2018;15:353–65.
25 Page MJ, McKenzie JE, Bossuyt PM, *et al*. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;372:n71.