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Variability in conceptualizations and measurement of genetic literacy

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ABSTRACT

Objective: To examine definitions and measures for genetic literacy in the published literature, and the associations between commonly utilized measures.
Methods: We completed a systematic review searching eight databases for empirical articles containing quantitative measures of genetic literacy. Articles were assessed for study properties, definitions, and measure characteristics. An online survey was then completed by 531 U.S. adults to examine correlations between frequently used genetic literacy measures.
Results: 92 articles met inclusion criteria for the systematic review. Articles rarely defined genetic literacy, and existing definitions showed inconsistencies in the knowledge and cognitive domains that comprise genetic literacy. Definitions frequently included objective conceptual knowledge, comprehension, and applied knowledge, however most measures only assessed objective or subjective knowledge. Genetic literacy measures were infrequently assessed for psychometric properties and the content domains assessed by measures varied considerably. Correlation analyses showed weak to moderate relationships between genetic literacy measures.
Conclusion: A comprehensive and consistent definition of genetic literacy and its cognitive and conceptual domains should be implemented to inform the development of concordant measurement tools and improve research and clinical care in genetics.
Innovation: We examine and compare definitions and measures of genetic literacy, suggest a more comprehensive definition, and recommendations for research development.

1. Introduction

Advances in technologies have greatly expanded the reach and utilization of genetic information. Genetic testing is increasingly being used in clinical contexts to inform disease prevention and clinical management [1,2], and millions of U.S. adults have accessed their genetic information through direct-to-consumer genetic testing [3-5]. With this expansion in reach and utilization of genetic information has come a recognition of the importance of developing effective approaches to support individuals in making informed decisions about genetic testing and using the information to manage their health. Genetic literacy is emerging as a critical aspect of genetics-related decision making and information processing by patients, the general public, and health care providers [6-8].

The construct of genetic literacy or genomic literacy has been used in various ways in the literature. A definition developed through a National Human Genome Research Institute workshop includes both domains of knowledge and cognitive skills: genomic health literacy is the capacity to obtain, process, understand, and use genomic information for health-related decision making [9]. Other definitions focus only on knowledge of genetic and/or genomic concepts, and often examine deficits in knowledge. One prior effort to develop a consensus definition of genetic literacy identified key domains of genetic knowledge, including nine domains of conceptual, sociocultural, and epistemic knowledge [10].

These varying conceptualizations of genetic literacy have led to different areas of emphasis and different findings in investigating the associations between genetic literacy and individual-level outcomes. In a prior literature review, we found that few studies (5 of 513) of communication of cancer-related genetic information considered genetic literacy [11]. Even among these few studies, the construct of genetic literacy was sometimes used to reflect knowledge about genetics and genomics and sometimes to encompass broader ranges of skills. As examples of the latter, in one study, genetic literacy was found to be positively related to learning from videotaped genetic counseling sessions [12], and, in another study, genetic literacy was positively related to forming opinions about surgical decisions [13]. Other research conceptualizing genetic literacy as including domains of skills has found that more difficult oral language during a genetic counseling session was associated with less satisfaction [14].

Other studies of genetic literacy have instead been based on an implicit model of a knowledge deficit about genetics, assessing only awareness and knowledge domains and their relationships with other variables. Such

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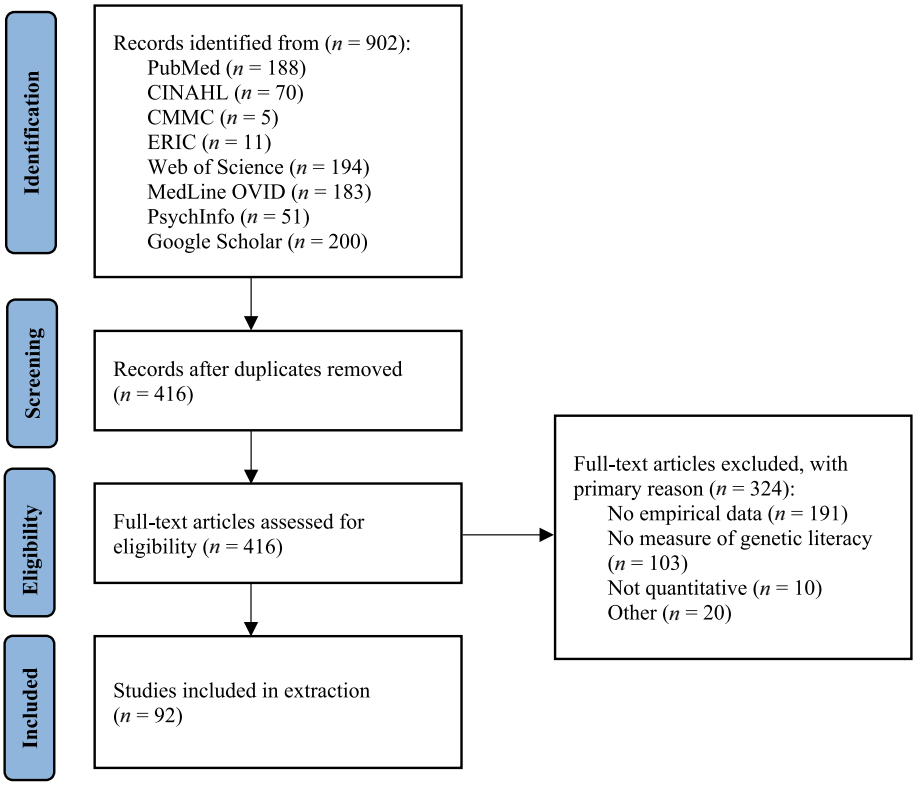

Fig. 1. PRISMA process of article identification and inclusion.

studies have discovered important gaps in knowledge about genetics and genomics. For example, one study that assessed genetic literacy as genetic testing awareness utilized a nationally representative sample and found limited awareness [15]. This type of assessment of genetic literacy as a knowledge deficit is consistent with a larger body of literature on genetic knowledge, which has shown that although individuals may be familiar with genetics-related terms, they have limited understanding of the underlying concepts [16-19]. Prior studies utilizing various assessments of genetic knowledge have also found disparities in genetic knowledge by sociodemographic factors such as education [18-24] and age [18,20-25].

Prior literature therefore has indicated that genetic literacy is critical in how patients and the general public understand and/or use genetic information. However, variability in how genetic literacy is conceptualized and assessed in the literature may hamper efforts to develop conceptual frameworks of the associations between genetic literacy and different outcomes. Because conceptualization of a construct may also drive measurement, these differing conceptualizations may lead to wide variability in how genetic literacy is assessed. In this review, we therefore examined definitions and measures used for genetic literacy in published health-related empirical articles. We also explored concordance between different commonly used measures of genetic literacy to investigate whether different measures are assessing the same underlying construct. We also investigated discriminant validity between genetic literacy, as assessed by different instruments, and two closely related constructs: subjective health literacy and numeracy. We highlight similarities and differences in definitions and measures used in the literature and make recommendations for advancing this area of the literature.

2. Methods

2.1. Systematic review

2.1.1. Inclusion criteria

We used broad inclusion criteria to identify original papers, dissertations and theses, conference abstracts, and posters (hereafter, "articles") that used a quantitative measure of genetic or genomic literacy. Measures were assessed based on title only; thus, any measure referred to as an assessment of "genetic/genomic literacy" met criteria, regardless of the measure's content or disease context. Articles with quantitative measures titled as "genetic knowledge" were eligible for inclusion if also referred to as a measure of genetic or genomic literacy within the publication. English-language articles with any geographic location, date of publication, and language of the measure were eligible. Articles were excluded if they did not contain original data, did not measure genetic literacy, or used solely qualitative methods. Though conference abstracts and posters were included in the review, we only extracted data on study design and administered genetic literacy measure(s) from these sources, excluding from analyses on definitions and measure format and content due to insufficient data.

2.1.2. Search strategy

A comprehensive literature search was conducted across seven databases from July to September 2021 (search strategy available in Supplemental Materials). After completing this first search, a second round was then done on Google Scholar, screening the first 200 non-duplicate articles in order to reach saturation. We identified 902 records (Fig. 1). After removing duplicates, 416 records remained, which were examined in full-text, including all supplemental files, for eligibility. We excluded 324 articles, leaving a final sample of $N = 92$, comprised of 89 papers, 2 conference abstracts, and 1 poster (full list of articles available in Supplemental Materials).

2.1.3. Data extraction

A data extraction form was developed by the authors and independently tested with 4 randomly selected articles. The final form (available in Supplemental Materials) included the following variables: study location and population; terminology and definitions; study design; measure(s) used; measure adaptation, validity, reliability, language, and item format(s); knowledge domains assessed; and vocabulary/content areas. To assess the content areas within a measure, we created a list of common conceptual domains from the genetic literacy measures. The articles were independently

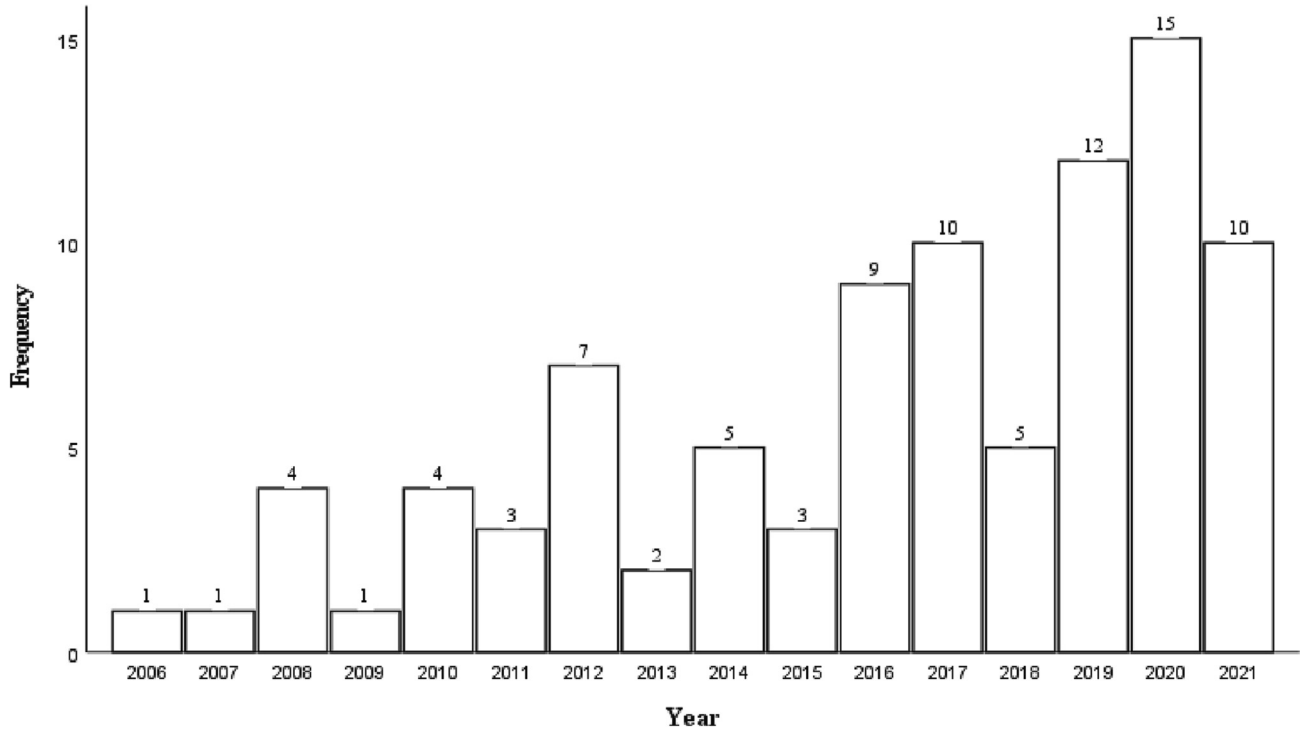

Fig. 2. Frequency of publications with a genetic literacy measure by year.

reviewed by the authors. Data extraction was performed manually using REDCap [26,27].

2.1.4. Data analysis

Descriptive analyses were performed using SPSS [28]. Definitions were thematically grouped during analysis according to cognitive domains.

2.2. Survey

2.2.1. Survey design

We conducted an English-language survey of a convenience sample of U.S. adults utilizing a Qualtrics Panel in July 2022 (Qualtrics, Provo, UT). A quota sampling scheme was utilized to oversample for respondents with lower educational attainment (30% with a high school diploma or less). There were 777 responses. After excluding ineligible respondents ($n = 216$) and respondents with missing data in the literacy and numeracy measures ($n = 22$), $N = 539$ participants were included in analysis.

We included six genetic literacy measures that were identified as having been used 3 or more times in our review[1]:

The Genetic Literacy and Comprehension (GLAC) measure [29] contains 8 vocabulary familiarity items (assessed as "I am familiar with this term" on a scale of 1 'Strongly Disagree' to 7 'Strongly Agree') and 8 fill-in-the-blank multiple-choice items related to each vocabulary term (scored as correct or incorrect). Familiarity scores were averaged and added to total correct fill-in-the-blank items for a combined score (range 1-15).

We included two available sub-scales from Ishiyama et al. [22]: Subjective and Objective Understanding. The Subjective sub-scale rated 5 terms with options "know the meaning of the term" (2), are "aware of the term" (1), or had "never heard of the term" (0). The Objective sub-scale comprised 5 statements with response options "correct" (1), "incorrect" (0), and "don't know" (0). Sub-scores were converted to be out of 10 points total and then combined (range 0-20).

The Genetic Knowledge Index (GKI) [32] included 6 true/false items. Correctly answered items were scored as 1, and incorrect items as '0'. Scores were summed (range 0-6).

Fitzgerald-Butt et al.'s (FB) [33] measure of genetic knowledge included 18 statements with response options of true/false/unsure. Correct answers were scored '1', with incorrect/unsure responses earning '0'. Sum scores ranged 0-18.

The Genetic Sequencing Knowledge (GSK) measure [34] included 11 Likert items, with responses ranging from Strongly disagree to Strongly agree. Following standard scoring for this item based on direction and strength of agreement, possible scores ranged from 0-22.

The Genetics Literacy Assessment Instrument (GLAI) [35] contained 31 multiple-choice items. Items were scored as correct (1) or incorrect (0), and the total score (range 0-31) was converted to represent the percentage of items answered correctly.

The survey also contained the Subjective Numeracy Scale (SNS) [36], health literacy (HL) screener items [37-38], and demographic questions to examine the associations of these measures with the genetic literacy measures. Higher scores indicated greater literacy/numeracy. Demographic characteristics included gender identity, race, ethnicity, age, zip code, household income, health insurance status, and having prior genetic testing as a part of clinical care.

2.2.2. Analysis

Survey data was analyzed using SPSS [28]. Demographic characteristics were analyzed with descriptive statistics. Relationships between genetic literacy, subjective numeracy, and health literacy measures were examined using Pearson correlations. Statistical significance was assessed as $p < 0.05$. One-way ANOVAs were used to determine differences by demographic groups.

3. Results

3.1. Systematic review

3.1.1. Study characteristics

The articles were published between 2006 and 2021 (Fig. 2) and utilized genetic literacy measures with various study populations, most

[1] The REAL-G [30] and Genomic Nursing Concept Inventory (GNCI) [31] were not included despite meeting this criterion. The REAL-G assesses verbalization and pronunciation of terminology participant and thus could not be administered via online survey. We were unable to obtain the GNCI items.

commonly being general population (n = 26), undergraduate students (n = 15), patients (n = 13), and nursing students (n = 9) (Table 1). Over half of the studies (n = 52) were conducted in the United States. Only 29 papers explicitly specified the language of their genetic literacy measure, with English (n = 23) being most common.

3.1.2. Terminology and definitions

Of the 89 full-text papers (excluding 3 abstracts and posters), only 34 (38%) provided a definition for "genetic literacy" and/or "genomic literacy". Definitions were analyzed for content and categorized according to 4 cognitive domains (Table 2):

1. Objective conceptual knowledge: memorization and recall of genetics facts (n = 23)
2. Comprehension: ability to understand and interpret genetics material (n = 15)
3. Application: ability to correctly use genetics facts and apply material learned to new situations relating to personal (n = 21), societal (n = 11), or professional (n = 4) contexts
4. Print skills: reading and writing skills in relation to genetics concepts (n = 1)

Individual definitions ranged from inclusion of 1-4 domains (M = 2.21, SD = 0.84).

In addition, 22 papers used both the terms "genetic literacy" and "genomic literacy"; however, it was often unclear whether these terms were used as interchangeable or distinct concepts.

3.1.3. Genetic Literacy Measures

3.1.3.1. Instruments. We identified 110 genetic literacy measures in the articles. The REAL-G [30] was most frequently used (n = 10), followed by the GLAI [35] (n = 9), GLAC [29] (n = 9), GNCI [31] (n = 9), and GSK [34] (n = 5). Most papers (n = 95) specified the number of measure items (M = 16.6, SD = 11.79; range 1-63). Item formats were detailed in 80% of measures (n = 88) (Table 3).

We classified measures into 5 categories according to the type of task: Objective conceptual knowledge (n = 68) (including 19 word recognition measures); self-rated/self-reported knowledge (n = 16); comprehension (n = 2); applied knowledge (n = 1), and other (n = 3; self-rated confidence, prior training in genetics, terminology association). Thirty-one measures did not provide sufficient information to determine classification.

3.1.3.2. Adapted measures. About 41% of the genetic literacy measures (n = 45) were described as adapted, either explicitly or based on methods. Adaptions included shortening a measure, such as by omitting individual items or entire sections (n = 12); creating a new measure using items from existing measure(s), either directly or in modified form (n = 17); modifying items (n = 9); adding new items to a measure (n = 2); or translating a measure (n = 5). Five measures were described as adapted with no further details.

3.1.3.3. Word recognition. Nineteen measures were classified as word recognition, in which the participant indicated their level of familiarity, awareness, knowledge, or understanding of a list of terms. Eight of these measures also included another method of objective knowledge measurement, such as multiple choice or fill-in-the-blank questions. The number of words used within a measure ranged from 3-63 (M = 15.2, SD = 18.8). There were 124 unique words and 258 total words were identified across measures. Two measures did not provide the full list of words used in their vocabulary assessment, and were thus excluded from this count. The most frequently used terms were chromosome (n = 14), mutation (n = 11), gene (n = 10), DNA (n = 9), genome (n = 8), sporadic (n = 8), susceptibility (n = 8), variation (n = 8), genetic (n = 7), and heredity (n = 6). Less commonly occurring terms (<2) included pharmacogenomics, targeted therapy, personal genome DNA, and variant of unknown significance.

3.1.3.4. Conceptual domains. For other types of measures, we examined the item content. Items were provided by 82 measures, either in complete wording or as a general description. The number of different content

Table 1
Study designs and characteristics of included studies.

Characteristic	n (%)
Study population[a] (n = 100)	
General population	26 (26.0)
Undergraduate students	15 (15.0)
Patients	13 (13.0)
Nursing students	9 (9.0)
K-12 students/children and adolescents	5 (5.0)
Physicians	5 (5.0)
Pregnant women	5 (5.0)
Caregivers and parents	4 (4.0)
Faculty	3 (3.0)
Medical students	2 (2.0)
Other population	13 (13.0)
Population groups per study	
Mean (SD)	1.09 (0.32)
Range	1-3
1 group	85
2 groups	6
3 groups	1
Country of study (n = 96)	
United States	52 (54.2)
Japan	7 (7.3)
Australia	4 (4.2)
Canada	3 (3.1)
Turkey	3 (3.1)
United Kingdom	2 (2.1)
Italy	2 (2.1)
Belgium	1 (1.0)
Brazil	1 (1.0)
Ecuador	1 (1.0)
Egypt	1 (1.0)
Greece	1 (1.0)
Hong Kong	1 (1.0)
Indonesia	1 (1.0)
Lebanon	1 (1.0)
Nigeria	1 (1.0)
Ghana	1 (1.0)
Portugal	1 (1.0)
Russia	1 (1.0)
Ukraine	1 (1.0)
Sri Lanka	1 (1.0)
Switzerland	1 (1.0)
Not specified	8 (8.3)
Number of countries in study[b]	
Range	1-4
1 country	82
2 countries	1
4 countries	1
Language of measure (n = 100)	
English	23 (23.0)
Spanish	7 (7.0)
Turkish	2 (2.0)
Japanese	1 (1.0)
Russian	1 (1.0)
Greek	1 (1.0)
Chinese	1 (1.0)
French	1 (1.0)
Not stated	63 (63.0)
Languages per measure[b]	
Range	1-2
1 language	21
2 languages	8

[a] Only includes population group that took the genetic literacy measure.
[b] Not including studies that did not state country/language.

Table 2
Genetic literacy and genetic knowledge definitions and themes.

Definition	Objective conceptual knowledge	Comprehension/ Understanding	Applied knowledge - personal	Applied knowledge - societal	Applied knowledge- professional	Print skills
sufficient knowledge and appreciation of genetic principles to allow informed decision making for personal well-being and effective participation in social decisions on genetic issues [25,35,39-43]	X		X	X		
sufficient knowledge and appreciation of genetics principles, to allow informed decision-making for personal well-being [44]	X		X			
sufficient knowledge and understanding of genomic principles and practices to make informed decisions about one's personal well-being and the ELSI associated with society [45]	X	X	X	X		
sufficient knowledge and understanding of genetic principles to make decisions that sustain personal well-being and effective participation in social decisions on genetic issues [8]	X	X	X	X		
the currency necessary to apply genomic principles in the context of one's personal and/or professional roles [46]			X		X	
the knowledge needed to (1) make an informed decision for genomic testing, (2) appropriately apply genomic technologies and accurately interpret genomic data, and (3) participate in decisions about genetics and genomics policy questions as a member of society [47]	X		X	X		
Genetic knowledge, also known as genetic literacy, refers to an individual's ability to understand and appreciate the basic principles of genetics for informed decision-making. From a genomics perspective, this literacy should include an understanding that most common diseases (heart disease, diabetes, cancers) are complex diseases that are influenced by multiple genetic risk factors (that interact with one another as well as their environment), family history, and behavioral and lifestyle factors. To achieve genomic literacy, individuals should have the “capacity to obtain, process, and use genomic information for health-related decision-making” [48]		X	X			
the ability to understand genetic information and use it to make decisions about health [49]		X	X			
the extent to which individuals understand information about genetics that affects their lives [50]		X	X			
the ability of an individual to understand concepts important to the use of personal genetic information [51]			X			
having the skills to comprehend clinician-provided information about genetics [52]		X				
individuals' understanding the conceptions related to genetics and being able to associate these conceptions with their lives [53]		X	X			
Certain foundational knowledge, defined as genomic literacy, is necessary for nurses to achieve genomic competency [54]	X				X	
knowledge sufficient to develop genetic and genomic competency, as outlined in the Essentials competency documents (Consensus Panel on Genetic/Genomic Nursing Competencies, 2009) [31]	X				X	
knowledge of genetics and genomics as these topics relate to, and affect, professional nursing [and midwifery] practice [55]	X				X	
involves knowing the basic units of the genome and the rules through which they assemble into meaningful patterns as well as understanding the ways through which vast amounts of information can be generated from simple genomic elements [56]	X	X				
a person's basic knowledge about genetic science. It encompasses key genetic concepts, such as gene expression, transmission, and a basic understanding of the effect of genes on individual health [7]	X	X				
ability to recognize terms related to genetics is defined as genetic literacy [57]	X	X				
We focused on a specific facet of genetic literacy - the skills to comprehend provided information about genetics [13]		X				
Literacy not only reflects one's ability to read and write, but is also associated with one's ability to understand and remember complex information communicated verbally [58]		X				X
Boerwinkel et al. distinguished between different types of genetic literacy, such as conceptual knowledge (eg, knowledge of genetic concepts), sociocultural knowledge (ie, knowledge of applications of genetic technologies) and epistemic knowledge (ie, knowledge of meaning of genetic information). Particularly, knowledge about the uses of genetic data for research and privacy issues might have implications for people's risk and benefit perceptions and ultimately their WTS[a] [59]	X		X	X		
knowledge on genomics […] access to genomic information and [capability] of critically interpreting that information, as well as have the ability to regularly update this knowledge [60]	X	X				
an adequate knowledge that personally involves someone to comprehend and actively participate in genetic issues [61]	X	X	X			
the ability of an individual to understand concepts important to the use of personal genetic information… and includes the concept of active application of genetic knowledge for informed decision-making [62]		X				
both the ability to decode scientific terminology specific to genetics and a familiarity with genetics terms [29]	X					
possessing the requisite knowledge and skills to ‘manage uncertainty and to participate as a full partner in a prevention-based healthcare system that is increasingly informed by genetic perspectives’ [63]	X		X			

(continued on next page)

Table 2 (*continued*)

Definition	Objective conceptual knowledge	Comprehension/ Understanding	Applied knowledge - personal	Applied knowledge - societal	Applied knowledge- professional	Print skills
the working knowledge of genetics and related areas, including genomics, pharmacogenomics and gene therapy [64]	X					
a capacity or empowerment for democratic and informed decision-making and participation around genetic issues [18]			X			

[a] WTS: willingness-to-share.

Table 3
Item formats for genetic literacy measures.

Characteristics	n (%)
Item Format (n = 110)	
Multiple choice	34 (25.2)
True/false; Correct/incorrect	28 (20.7)
Likert scale	23 (17.0)
Vocabulary recognition	12 (8.9)
Fill-in-the-blank	5 (3.7)
Open-ended	4 (3.0)
Yes/No	3 (2.2)
Slider	2 (1.5)
Know/Don't Know	1 (0.7)
Agree/Disagree	1 (0.7)
tem format not specified	22 (16.3)
Range of Item Formats[a]	1–4
1 type	72
2 types	9
3 types	5
4 types	2

[a] Does not include 22 measures that did not specify item format.

domains found within a measure ranged from 1 to 18 (M = 4.7, SD = 4.2). The most frequent domains that appeared in more than 10% of measures were genetic material (n = 43), genetic mutations (n = 36), autosomal disorders (n = 26), sexual reproduction and heredity (n = 22), gene-environment interaction (n = 19), functions of genetic material (n = 18), genetic technology (n = 13), family health history (n = 12), genetic laws, privacy, and ethics (n = 12), and genetic variations (n = 11). The remaining concepts appeared in items in less than 10% of measures.

Within a single content domain, items also differed in regard to substance, complexity, and difficulty. Table 4 exemplifies this variability, demonstrating that one concept may be assessed differently dependent on the measure used. For this analysis, items were organized by populations: medical professionals (e.g., physicians, faculty, nursing students) vs. non-medical professionals (e.g., general public, students). Medical professionals may need a more comprehensive understanding of genetics, and thus items intended for that population may be more complex. However, variability within items in a single content domain remained even within population categories. There was also little consistency in content in measures created for medical professionals to assess genetic literacy. For example, of the 21 measures given to medical professionals, only one included an item assessing knowledge on "newer genetic/genomic technologies (i.e., high-throughput sequencing, genotyping and copy number variation analysis)" [65].

3.1.3.5. Validity and reliability. Validity and reliability were determined by article description (e.g., "a validated measure") or provision of a coefficient (e.g., α). Less than half (40%; n = 44) of the genetic literacy measures were described as validated, although only 25 of these (56.8%) provided details. Validation methods ranged from 1-3 for an individual measure, though most (n = 16) used only one type. Content or face validity was the most

Table 4
Sample genetic literacy items by content domain and population.

Domain	Sample Item 1	Sample Item 2	Sample Item 3	Sample Item 4
Genetic Material	There are different initiation codons.[1]	Genotype refers to:[2]	Which factors mostly influence the Human Microbiome?[1]	'Non-coding' DNA describes DNA that does what?[1]
Genetic Mutations	What fraction of genetic variants are known to cause disease?[1]	I do not feel that I have knowledge on genetic disorders.[1]	The carrier of a disease gene can be completely healthy.[1]	A person with altered (mutated) gene may be completely healthy.[2]
Genetic similarities and variations amongst humans	Imagine you are examining the DNA sequence of two unrelated people. What percentage of the sequence do you anticipate will be identical between these people?[2]	On average, how much of their total DNA is the same in two people selected at random?[1]	Genetic variation is much greater within traditional human ethnic groups than among them. Superficial phenotypic differences do not reflect the high degree of genetic relatedness among traditional ethnic group.[1]	On average, a person has half their genes in common with their siblings.[1]
Genetic technology	What is an example of an unexpected consequence when current genetic technologies are used?[1]	Imagine the following situation: "As a researcher, you sequence a genomic fragment. Do you have any idea how you would proceed to identify the gene(s) present? If so, indicate the main procedures that you would follow to identify the gene(s) present in that sequence.[1]	Applications of FISH.[2]	I am knowledgeable about the principles of cytogenetics and molecular genetic techniques.[2]
Genetic laws, privacy, and ethics	The U.S. Federal Law entitled the "Genetic Information Non-Discrimination Act (GINA)" prohibits:[1]	Databases, known as genebanks, are free access resources.[1]	Huntington's disease is a genetic disorder caused by a dominant gene. Symptoms begin in adulthood and the disease is ultimately fatal. What is an ethical dilemma presented by Huntington's disease when a parent is diagnosed with the disease?[1]	What is GINA?[2]
Traits and Behaviors	Genetic variants in the intergenic regions of the genome (between genes) can impact traits.[1]	Like humans, plant cells and fungi have genes that determine their traits.[1]	Single genes directly control specific human behaviors.[1]	Can we predict a person's behaviour from looking at their DNA sequence?[1]

[1] Measure created for non-medical professionals.
[2] Measure created for medical professionals/students.

Table 5
Survey participant characteristics.

Characteristics	*n* (%)
Age (n = 535)	
Mean (SD)	39 (16.96)
Range	18–87
Gender (n = 539)	
Female	378 (70.1)
Male	151 (28.0)
Non-binary	9 (1.7)
Other	1 (0.2)
Race (n = 539)	
African-American/Black	99 (18.4)
Asian	20 (3.7)
Native American/Alaska Native	8 (1.5)
Other	14 (2.6)
Pacific Islander/Native Hawaiian	5 (0.9)
White/Caucasian	376 (69.8)
Multi-racial	17 (3.1)
Ethnicity (n = 538)	
Latino/Hispanic	77 (14.3)
Non-Hispanic/non-Latino	430 (79.9)
Other	31 (5.8)
Highest level of education (n = 539)	
Junior high or some High school	16 (3.0)
High school degree or GED	146 (27.1)
Associate degree	68 (12.6)
Some college	144 (26.7)
College degree	112 (20.8)
Graduate degree	53 (9.8)
Health Insurance (n = 539)	
No insurance	67 (12.4)
Private insurance	230 (42.7)
Public insurance	242 (44.9)
Previous genetic testing (n = 539)	
No previous genetic testing	473 (87.8)
Don't know	40 (7.4)
Had previous genetic testing	26 (4.8)
Household Income (n = 539)	
<$25,000	107 (19.9)
$25,000–$49,999	137 (25.4)
$50,000–$74,999	120 (22.3)
$75,000–$99,999	75 (13.9)
≥$100,000	75 (13.9)
Prefer not to answer	25 (4.6)

commonly used (n = 16), with less frequent methods described as concurrent validity (n = 5), construct validity (n = 4), predictive validity (n = 3), criterion validity (n = 1), and discriminant validity (n = 1).

Reliability was assessed for about one-third (n = 38) of the genetic literacy measures. Most studies (n = 33) assessed one type of reliability, most frequently inter-item utilizing Cronbach's alpha (n = 33); however, methods described as test-retest (n = 4), Pearson correlation (n = 1), Spearman-Brown (n =1), and item-total correlation (n = 1) were also identified.

3.2. Survey

Of the 539 participants, 30.1% had a high school degree or less (Table 5). Participants averaged 39 years of age, most identified as female (70.1%), White (69.8%), non-Hispanic/Latino (79.9%), with health insurance (87.6%), and no history of clinical genetic testing (87.8%).

The genetic literacy measures were all significantly associated, however, these were generally weak to moderate correlations [66] ($p < .001$ unless otherwise stated; see Table 6). Small correlations were found between Ishiyama and the GLAC (r = .232), GKI (r = -.105, p = .015), and GLAI (r = .104, p = .016), as well as between the GKI and GSK (r = .242). Moderate correlations (r = .300 to r = .477) were found between the following measures: GLAC/GKI, GLAC/GSK, Ishiyama/FB, Ishiyama/GSK, GLAI/GKI, GLAI/FB, and GLAI/GSK. Large correlations were found only between GLAC/GLAI and GLAC/FB (r = .506, r = .536).

SNS had a weak relationship with GLAC, Ishiyama, FB, and GLAI (r = .211 to r = .278), and was moderately correlated with GSK (r = .369). HL was weakly correlated with FB and GSK (r = .269 and r = .228), and moderately associated with GLAC and GKI (r = .346 and r = .397). Differences in mean scores by demographic characteristics can be found in the Appendix.

4. Discussion and conclusion

4.1. Discussion

The primary finding from our review of genetic literacy definitions and measurement in the published literature is that most papers do not define the construct which they are measuring, and amongst those that do, there is a lack of consistency in the domains that are included in the definition. Furthermore, there was incongruence between the definitions of genetic literacy and the actual cognitive domains being assessed by the measures. Both comprehension and applied knowledge were included in most definitions, yet only two articles (Abrams et al., 2015[8]; Abrams et al., 2016 [13]) appraised comprehension, and one article (Ward, 2011[54]) appraised applied knowledge. Nearly all measures instead assessed objective knowledge, which demonstrates an ability to memorize and recall, rather than the capacity to understand, interpret, or use genetic information. These findings therefore highlight that measures of genetic literacy are not assessing the applied domains included in most definitions. Future research directions could include examining changes in definitions and measures of genetic literacy over time, and the influence of national meetings, funding opportunities or public health initiatives with these trends.

We also found that the content domains included within measures of genetic literacy varied considerably in the number of domains used in an individual measure (i.e., most measures were only assessing knowledge in a few topical areas) and in the content and difficulty of the individual items used to represent knowledge within each domain across measures and for medical and non-medical populations. These findings therefore show a lack of agreement on what the extent of knowledge in specific genetic

Table 6
Means, standard deviation, and pearson correlation matrix for literacy and numeracy survey measures (n = 539).

	M	SD	1	2	3	4	5	6	7	8
1. GLAC	11.68	2.39								
2. Ishiyama	11.89	3.82	.232**							
3. GKI	4.18	1.41	.450**	–.105*						
4. FB	12.00	3.65	.536**	.403**	.381**					
5. GSK	7.30	4.89	.358**	.300**	.242**	.476**				
6. GLAI(%)	33.80	16.65	.506**	.104*	.476**	.456**	.477**			
7. SNS	4.04	0.74	.223**	.278**	.008	.248**	.369**	.211**		
8. HL	8.25	2.74	.346**	–.084	.397**	.269**	.228**	.377**	–.005	

GLAC: Genetic Literacy and Comprehension [29]; Ishiyama [22]; GKI: Genetic Knowledge Index [32]; FB: Fitzgerald-Butt measure [33]; GSK: Genome Sequencing Knowledge [34]; GLAI: Genetic Literacy Assessment Instrument [35]; SNS: Subjective Numeracy Scale [36]; HL: Health Literacy measure [37,38].

* p <.05

** p < .001

concepts should be to meet the criteria for "genetically literate", and whether or how this expectation of expertise differs for medical professionals compared to the general public. Similarly, word recognition measures of genetic literacy differed in the terms used. Self-reported knowledge was the second most common format of measurement. However, self-reported, or subjective, knowledge differs from objective conceptual knowledge, and thus it is critical to distinguish between the two formats in presenting findings.

Findings on the disparity in conceptualization and operationalization from the systematic review were corroborated by our survey results, with most genetic literacy measures showing only small to moderate correlations. Taken together, our findings therefore highlight that measures described as the same construct of genetic literacy are in fact likely measuring different component domains, leading to inconsistencies in the literature reporting on the associations of genetic literacy with different outcome variables. There was a notable lack of significant relationships between health literacy with both Ishiyama and subjective numeracy, as well as between subjective numeracy and GKI, suggesting that these are measuring different constructs.

Beyond the incongruence within and between definitions and measures, we also found that most articles did not report on the psychometric properties of genetic literacy measures in their study populations. In addition, amongst those that did report on these properties, use of concurrent and discriminant validity were minimal. Furthermore, though many measures were described as adapted, the method of adaptation was often unclear, as was whether the psychometric properties of previously validated and reliable measures were re-evaluated after being adapted. These findings therefore highlight substantial needs in the measurement of genetic literacy to develop valid and reliable measures that are consistent with the definition of genetic literacy utilized.

4.2. Innovation

This study is one of the first to review the literature and examine how genetic literacy is being defined and measured. Future directions can be informed by existing literature on literacy in other domains. Health literacy had often been defined as "the degree to which individuals have the capacity to obtain, communicate, process, and understand health information and services needed to make appropriate health decisions" [67], and, more recently, was updated in the U.S. as, "the degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others" [67]. The European Health Literacy Project [68] similarly concluded that health literacy should include multiple domains of applied knowledge and skills, identifying four dimensions of health literacy: accessing, understanding, appraising, and applying information to make everyday health decisions.

Psychological literacy is commonly defined by 9 attributes: basic knowledge and vocabulary; scientific thinking and evaluation of information; problem solving; application to personal, societal, and professional context; ethical action; competence in use and evaluation of information; effective communication skills; respect for diversity; and insight and reflection [69]. Media literacy was defined [70] as the "ability…to access, analyze, and produce information", and more recently as "life skills that are necessary for full participation in our…society", including the ability to access and comprehend information; analyze, evaluate, and create content [71]. Thus, there is clear agreement on having objective knowledge, comprehension, communication, and application as the cognitive domains that encompass literacy across disciplines.

Bowling's [35] commonly used definition describes genetic literacy as "sufficient knowledge and appreciation of genetic principles [*i.e. comprehension*] to allow informed decision making for personal well-being and effective participation in social decisions on genetic issues [*i.e. application*]", with variations of this also including understanding [*i.e. comprehension*] [8,45]. We propose a further expansion upon this, defining genetic literacy as **sufficient knowledge and understanding of genetic information to allow for effective communication and application of learned information and informed decision-making in personal, societal, and professional contexts**. The implementation of a consensus definition of genetic literacy and its attributes can subsequently be used to develop a standardized measure of genetic literacy including these applied domains to create alignment between conceptualization and operationalization. Along with this, it is critical that genetic literacy measures are psychometrically sound, including more extensive validation examining dimensions such as concurrent and discriminant validity. We also highlight the importance of concordance between the name of a measure and its component domains to improve validity of measures of genetic literacy, as well as to utilize a common conceptualization of genetic literacy and create clear distinction from related domains, such as knowledge or awareness. Lastly, there is a need to distinguish between the use of the terms "genetic" and "genomic" for conceptual clarity.

5. Conclusion

Genetic literacy is a growing area of research, and it is important to note that new measures may exist or have since been developed that were not included in this review. However, prior reviews of genetic literacy measures show mixed results overall [73-74,75], thus making it difficult to draw conclusions on the current state of genetic literacy levels or to determine specific areas of strength or deficits. This discrepancy may in part be attributed to the dissimilarity of measurement tools and a lack of focus due to unstated and/or inconsistent definitions, as demonstrated in the current study. Further research and development on conceptualization and measurement is therefore necessary and will help progress genetic literacy into a more robust field of research, allowing for improved assessment of its related outcomes, and better informing clinical care and individuals in a society of rapidly advancing genetic and genomic technologies and discoveries.

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Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.pecinn.2023.100147.

References

[1] Bajguz D, Danylchuk NR, Czarniecki M, Selig JP, Sutphen R, Kaylor J. Utilization of genetic testing: Analysis of 4,499 prior authorization requests for molecular genetic tests at four US regional health plans. J Genet Couns. 2021;31:771–80. https://doi.org/10.1002/jgc4.1543.

[2] Pritchard D, Goodman C, Nadauld LD. Clinical utility of genomic testing in cancer care. JCO Precis Oncol. 2022;6:e2100349. https://doi.org/10.1200/PO.21.00349.

[3] Regalado A. More than 26 million people have taken an at-home ancestry test. MIT Technology Review; 2019, February 11. Retrieved from: https://www.technologyreview.com/2019/02/11/103446/more-than-26-million-people-have-taken-an-at-home-ancestry-test/.

[4] 23andMe. 23andMe Reports FY2022 Fourth Quarter and Full Year Financial Results. Retrieved from: https://mediacenter.23andme.com/; 2022, May 26.

[5] Ancestry. Ancestry 2021 Impact Report. Retrieved from: https://www.ancestry.com/corporate/annual-impact-report; 2022, March 23.

[6] Christensen KD, Jayaratne TE, Roberts JS, Kardia SL, Petty EM. Understandings of basic genetics in the United States: results from a national survey of black and white men and women. Public Health Genomics. 2010;13:467–76. https://doi.org/10.1159/000293287.
[7] Pearson YE, Liu-Thompkins Y. Consuming direct-to-consumer genetic tests: the role of genetic literacy and knowledge calibration. J Public Policy Mark. 2012;31:42–57. https://doi.org/10.1509/jppm.10.066.
[8] Abrams LR, McBride CM, Hooker GW, Cappella JN, Koehly LM. The many facets of genetic literacy: assessing the scalability of multiple measures for broad use in survey research. PloS One. 2015;10:e0141532. https://doi.org/10.1371/journal.pone.0141532.
[9] Hurle B, Citrin T, Jenkins JF, Kaphingst KA, Lamb N, Roseman JE, et al. What does it mean to be genomically literate?: National Human Genome Research Institute Meeting Report. Genet Med. 2013;15:658–63. https://doi.org/10.1038/gim.2013.14.
[10] Boerwinkel DJ, Yarden A, Waarlo AJ. Reaching a consensus on the definition of genetic literacy that is required from a twenty-first-century citizen. Sci Educ. 2017;26:1087–114. https://doi.org/10.1007/s11191-017-9934-y.
[11] Kaphingst KA, Peterson E, Zhao J, Gaysynsky A, Elrick A, Hong SJ, et al. Cancer communication research in the era of genomics and precision medicine: a scoping review. Genet Med. 2019;21:1691–8. https://doi.org/10.1038/s41436-018-0402-0.
[12] Portnoy DB, Roter D, Erby LH. The role of numeracy on client knowledge in BRCA genetic counseling. Patient Educ Couns. 2010;81:131–6.
[13] Abrams LR, Koehly LM, Hooker GW, Paquin RS, Capella JN, McBride CM. Media exposure and genetic literacy skills to evaluate Angelina Jolie's decision for prophylactic mastectomy. Public Health Genomics. 2016;19:282–9. https://doi.org/10.1159/000447944.
[14] Roter DL, Erby LH, Larson S, Ellington L. Assessing oral literacy demand in genetic counseling dialogue: preliminary test of a conceptual framework. Soc Sci Med. 2007;65:1442–57. https://doi.org/10.1016/j.socscimed.2007.05.033.
[15] Krakow M, Ratcliff CL, Hesse BW, Greenberg-Worisek AJ. Assessing genetic literacy awareness and knowledge gaps in the US population: results from the Health Information National Trends survey. Public Health Genomics. 2017;20:343–8. https://doi.org/10.1159/000489117.
[16] Catz DS, Green NS, Tobin JN, Lloyd-Puryear MA, Kyler P, Umemoto A, et al. Attitudes about genetics in underserved, culturally diverse populations. Community Genet. 2005;8:161–72. https://doi.org/10.1159/000086759.
[17] Lanie AD, Jayaratne TE, Sheldon JP, Kardia SL, Anderson ES, Feldbaum M, et al. Exploring the public understanding of basic genetic concepts. J Genet Couns. 2004;13:305–20. https://doi.org/10.1023/b:jogc.0000035524.66944.6d.
[18] Molster C, Charles T, Samanek A, O'Leary P. Australian study on public knowledge of human genetics and health. Public Health Genomics. 2009;12:84–91.
[19] Haga SB, Rosanbalm KD, Boles L, Tindall GM, Livingston TM, O'Daniel JM. Promoting public awareness and engagement in genome sciences. J Genet Couns. 2013;22:508–16. https://doi.org/10.1007/s10897-013-9577-3.
[20] Calsbeek H, Morren M, Bensing J, Rijken M. Knowledge and attitudes towards genetic testing: a two year follow-up study in patients with asthma, diabetes mellitus and cardiovascular disease. J Genet Couns. 2007;16:493–504. https://doi.org/10.1007/s10897-006-9085-9.
[21] Henneman L, Timmermans DR, van der Wal G. Public experiences, knowledge and expectations about medical genetics and the use of genetic information. Community Genet. 2004;7:33–43. https://doi.org/10.1159/000080302.
[22] Ishiyama I, Nagai A, Muto K, Tamakoshi A, Kokado M, Mimura K, et al. Relationship between public attitudes toward genomic studies related to medicine and their level of genomic literacy in Japan. Am J Med Genet A. 2008;146:1696–706. https://doi.org/10.1002/ajmg.a.32322.
[23] Jallinoja P, Aro AR. Knowledge about genes and heredity among Finns. New Genet Soc. 1999;18:101–10. https://doi.org/10.1080/14636779908656892.
[24] Rose A, Peters N, Shea JA, Armstrong K. The association between knowledge and attitudes about genetic testing for cancer risk in the United States. J Health Commun. 2005;10:309–21. https://doi.org/10.1080/10810730590950039.
[25] Ashida S, Goodman M, Pandya C, Koehly LM, Lachance C, Stafford J, et al. Age differences in genetic knowledge, health literacy and causal beliefs for health conditions. Public Health Genomics. 2011;14:307–16. https://doi.org/10.1159/000316234.
[26] Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap)–a metadata-driven methodology and workflow process for providing translational research informatics support. J Biomed Inform. 2009;42:377–81. https://doi.org/10.1016/j.jbi.2008.08.010.
[27] Harris PA, Taylor R, Minor BL, Elliot V, Fernandez M, O'Neal L, et al. The REDCap consortium: Building an international community of software platform partners. J Biomed Inform. 2019;95:103208. https://doi.org/10.1016/j.jbi.2019.103208.
[28] IBM Corp. Released. IBM SPSS Statistics for Windows, Version 28.0. Armonk, NY: IBM Corp; 2021.
[29] Hooker GW, Peay H, Erby L, Bayless T, Biesecker BB, Roter DL. Genetic literacy and patient perceptions of IBD testing utility and disease control: a randomized vignette study of genetic testing. Inflamm Bowel Dis. 2014;20:901–8. https://doi.org/10.1097/MIB.0000000000000021.
[30] Erby LH, Roter D, Larson S, Cho J. The rapid estimate of adult literacy in genetics (REALG): a means to assess literacy deficits in the context of genetics. Am J Med Genet A. 2008;146:174–81. https://doi.org/10.1002/ajmg.a.32068.
[31] Ward LD, Haberman M, Barbosa-Leiker C. Development and psychometric evaluation of the genomic nursing concept inventory. J Nurs Educ. 2014;53:511–8. https://doi.org/10.3928/01484834-20140806-04.
[32] Furr LA, Kelly SE. The Genetic Knowledge Index: developing a standard measure of genetic knowledge. Genet Test. 1999;3:193–9. https://doi.org/10.1089/gte.1999.3.193.
[33] Fitzgerald-Butt SM, Bodine A, Fry KM, Ash J, Zaidi AN, Garg V, et al. Measuring genetic knowledge: a brief survey instrument for adolescents and adults. Clin Genet. 2016;89:235–43. https://doi.org/10.1111/cge.12618.
[34] Kaphingst KA, Blanchard M, Milam L, Pokharel M, Elrick A, Goodman MS. Relationships between health literacy and genomics-related knowledge, self-efficacy, perceived importance, and communication in a medically underserved population. J Health Commun. 2016;21:58–68. https://doi.org/10.1080/10810730.2016.1144661.
[35] Bowling BV, Acra EE, Wang L, Myers MF, Dean GE, Markle GC, et al. Development and evaluation of a genetics literacy assessment instrument for undergraduates. Genetics. 2008;178:15–22. https://doi.org/10.1534/genetics.107.079533.
[36] Fagerlin A, Zikmund-Fisher BJ, Ubel PA, Jankovic A, Derry HA, Smith DM. Measuring numeracy without a math test: Development of the Subjective Numeracy Scale (SNS). Med Decis Making. 2007;27:672–80. https://doi.org/10.1177/0272989X07304449.
[37] Chew LD, Griffin JM, Partin MR, Noorbaloochi S, Grill JP, Snyder A, et al. Validation of screening questions for limited health literacy in a large VA outpatient population. J Gen Intern Med. 2008;23:561–6. https://doi.org/10.1007/s11606-008-0520-5.
[38] Wynia MK, Osborn CY. Health literacy and communication quality in health care organizations. J Health Commun. 2010;15:102–15. https://doi.org/10.1080/10810730.2010.499981.
[39] Raker R. Genetic Literacy and the Acquisition of Clinical Genetics Knowledge in Medical Students (Doctoral dissertation). Retrieved from the University of Pittsburgh ProQuest Dissertations Publishing; 2021. Accession Order No. ATT 29100141.
[40] Cebesoy ÜB, Tekkaya C. Pre-service science teachers' genetic literacy level and attitudes towards genetics. Procedia Soc Behav Sci. 2012;31:56–60. https://doi.org/10.1016/j.sbspro.2011.12.016.
[41] Moskalik CL. I. Impact of a Genetics Education Workshop on Faculty Participants II. Investigations of Undergraduate Genetic Literacy (Master's thesis). Retrieved from OhioLINK Electronic Theses and Dissertations Center. http://rave.ohiolink.edu/etdc/view?acc_num=ucin1195583851; 2007.
[42] Acra EE. Assessing genetic literacy in undergraduates (Master's thesis). Retrieved from OhioLINK Electronic Theses and Dissertations Center. http://rave.ohiolink.edu/etdc/view?acc_num=ucin1155217000; 2006.
[43] Raible DM. Assessing Genetic Literacy and the Impact of Instruction at the Undergraduate Level (Master's thesis). Retrieved from OhioLINK Electronic Theses and Dissertations Center. http://rave.ohiolink.edu/etdc/view?acc_num=ucin1276975558; 2010.
[44] Hamilton JG, Hutson SP, Frohnmayer AE, Han PK, Peters JA, Carr AG, et al. Genetic information-seeking behaviors and knowledge among family members and patients with inherited bone marrow failure syndromes. J Genet Couns. 2015;24:760–70. https://doi.org/10.1007/s10897-014-9807-3.
[45] Stefanile A. A study of secondary school students' participation in a novel course on genomic principles and practices (Doctoral dissertation). Retrieved from Columbia Academic Commons; 2020. https://doi.org/10.7916/d8-94kq-e983.
[46] LeBlanc ÉM. Needs analysis of genetics and genomics in communication sciences and its disorders: evidence for change (Doctoral dissertation). Retrieved from Columbia Academic Commons; 2012. https://doi.org/10.7916/D81Z4BHC.
[47] Linderman MD, Suckiel SA, Thompson N, Weiss DJ, Roberts JS, Green RC. Development and validation of a comprehensive genomics knowledge scale. Public Health Genomics. 2021;24:291–303. https://doi.org/10.1159/000515006.
[48] Schmidlen TJ, Scheinfeldt L, Zhaoyang R, Kasper R, Sweet K, Gordon ES, et al. Genetic knowledge among participants in the Coriell Personalized Medicine Collaborative. J Genet Couns. 2016;25:385–94. https://doi.org/10.1007/s10897-015-9883-z.
[49] Bowen DJ, Wang C, Cole AM, Norquist BM, Knerr S, Devine D, et al. Design of a study to implement population-based risk assessment for hereditary cancer genetic testing in primary care. Contemp Clin Trials. 2021;101:106257. https://doi.org/10.1016/j.cct.2020.106257.
[50] Seven M, Paşalak Şİ, Sahin E, Akyuz A. Genetic literacy of pregnant women and their use of prenatal screening and diagnostic tests in Turkey. J Genet Couns. 2019;28:578–86. https://doi.org/10.1002/jgc4.1082.
[51] Bonkowski ES. Effects of communication complexity on analogue clients in a video cancer genetic counseling session (Master's thesis) Retrieved from JScholarship Theses and Dissertations, Electronic (ETDs). https://jscholarship.library.jhu.edu/handle/1774.2/59217; 2018.
[52] Drelles K, Pilarski R, Manickam K, Shoben AB, Toland AE. Impact of previous genetic counseling and objective numeracy on accurate interpretation of a pharmacogenetics test report. Public Health Genomics. 2021;24:26–32. https://doi.org/10.1159/000512476.
[53] Erdoğan A, Özsevgeç LC, Özsevgeç T. A study on the genetic literacy levels of prospective teachers. Necatibey Facult Edu Electron J Sci Math Edu. 2014;8:19–37. https://doi.org/10.17522/nefefmed.67307.
[54] Ward LD. Development of the genomic nursing concept inventory (Doctoral dissertation). Retrieved from Washington State University ProQuest Dissertations Publishing; 2011. Accession Order No. ATT 3460449.
[55] Wright H, Zhao L, Birks M, Mills J. Genomic literacy of registered nurses and midwives in Australia: a cross-sectional survey. J Nurs Scholarsh. 2019;51:40–9. https://doi.org/10.1111/jnu.12440.
[56] Chapman R, Likhanov M, Selita F, Zakharov I, Smith-Woolley E, Kovas Y. New literacy challenge for the twenty-first century: genetic knowledge is poor even among well educated. J Community Genet. 2019;10:73–84. https://doi.org/10.1007/s12687-018-0363-7.
[57] Milo Rasouly H, Cuneo N, Marasa M, DeMaria N, Chatterjee D, Thompson JJ, et al. GeneLiFT: A novel test to facilitate rapid screening of genetic literacy in a diverse population undergoing genetic testing. J Genet Couns. 2021;30:742–54. https://doi.org/10.1002/jgc4.1364.
[58] Similuk MN, Yan J, Setzer MR, Jamal L, Littel P, Lenardo M, et al. Exome sequencing study in a clinical research setting finds general acceptance of study returning secondary genomic findings with little decisional conflict. J Genet Couns. 2021;30:766–73. https://doi.org/10.1002/jgc4.1367.

[59] Bearth A, Siegrist M. Psychological factors that determine people's willingness-to-share genetic data for research. Clin Genet. 2020;97:483–91. https://doi.org/10.1111/cge.13686.
[60] Nakamura S, Narimatsu H, Katayama K, Sho R, Yoshioka T, Fukao A, et al. Effect of genomics-related literacy on non-communicable diseases. J Hum Genet. 2017;62:839–46. https://doi.org/10.1038/jhg.2017.50.
[61] Rujito L, Nandhika T, Lestari DWD, Ferine M, Muhaimin A. Genetic literacy levels and genetic screening attitudes on medical students in Indonesia: A National survey. Malaysian. J Public Health Med. 2020;20:1–8. https://doi.org/10.37268/mjphm/vol.20/no.3/art.407.
[62] Giuse NB, Kusnoor SV, Koonce TY, Naylor HM, Chen SC, Blasingame MN, et al. Guiding oncology patients through the maze of precision medicine. J Health Commun. 2016;21:5–17. https://doi.org/10.1080/10810730.2015.1131772.
[63] East KM, Hott AM, Callanan NP, Lamb NE. Biotech 101: an educational outreach program in genetics and biotechnology. J Genet Couns. 2012;21:704–12. https://doi.org/10.1007/s10897-012-9491-0.
[64] Gallop L, Chapman R, Selita F, Kovas Y. Effects of education and media framing on genetic knowledge and attitudes. EpSBS. 2017;33:121–41. https://doi.org/10.15405/epsbs.2017.12.13.
[65] Chow-White P, Ha D, Laskin J. Knowledge, attitudes, and values among physicians working with clinical genomics: a survey of medical oncologists. Hum Resour Health. 2017;15:42. https://doi.org/10.1186/s12960-017-0218-z.
[66] J. Cohen. Statistical Power Analysis for the Behavioral Sciences. 2nd ed. Hillsdale, New Jersey: Lawrence Erlbaum Associates, Publishers; 1988; 1988.
[67] Office of Disease Prevention and Health Promotion. Healthy people 2030. U.S. Department of Health and Human Services. https://health.gov/healthypeople/priority-areas/health-literacy-healthy-people-2030.
[68] Doyle G, Cafferkey K, Fullam J. The European Health Literacy Survey: Results from Ireland. Dublin, Ireland: University College Dublin; 2012.
[69] McGovern TV, Corey L, Cranney J, Dixon Jr WE, Holmes JD, Kuebli JE, et al. Psychologically literate citizens. In: Halpern DF, editor. Undergraduate education in psychology: A blueprint for the future of the discipline. American Psychological Association; 2010. p. 9–27. https://doi.org/10.1037/12063-001.
[70] Aufderheide P, Firestone C. Media literacy: A report of the national leadership conference on media literacy. Washington, D.C: The Aspen Institute; 1993. ERIC ED365294.
[71] Hobbs R. Digital and media literacy: A plan of action. Washington, D.C: The Aspen Institute; 2010. ERIC ED523244.
[73] Vassy JL, O'Brien KE, Waxler JL, Park ER, Delahanty LM, Florez JC, et al. Impact of literacy and numeracy on motivation for behavior change after diabetes genetic risk testing. Med Decis Making. 2012;32:606–15. https://doi.org/10.1177/0272989X11431608.
[74] Dar-Nimrod I, MacNevin G, Godwin A, Lynch K, Magory Cohen T, Ganesan A, et al. Genetic knowledge within a national Australian sample: comparisons with other diverse populations. Public Health Genomics. 2018;21:133–43. https://doi.org/10.1159/000496381.
[75] Driver MN, Kuo SI, Dick DM. Genetic feedback for psychiatric conditions: Where are we now and where are we going. Am J Med Genet B Neuropsychiatr Genet. 2020;183:423–32. https://doi.org/10.1002/ajmg.b.32815.