

APPENDIX

Exhibit 1. Methods.

In 2015, the GPHAC was formed under the auspices of the Roundtable on Genomics and Precision Health at the National Academies of Sciences, Engineering, and Medicine. The authors of this paper are participants in the GPHAC Cascade Screening sub-group, which aims to identify and develop best practices for identifying and testing at-risk relatives of those diagnosed with familial hypercholesterolemia (FH), Lynch syndrome (LS), and/or hereditary breast and ovarian cancer (HBOC).(1) This work reflects the efforts of this GPHAC sub-group. We identified a need to summarize the current literature and state-level policies related to cascade screening.

Data sources and searches. We performed a scoping review of the current US and non-US literature on cascade screening for genetic disorders. We searched Medline, Embase, Global Health, PsycInfo, CINAHL, and Scopus databases for literature on five subtopics related to cascade screening: barriers/facilitators, cost effectiveness, implementation, national health systems/registries, and policy interventions. Specific search strategies for each database can be found in Appendix Exhibit 2 (table). We identified and removed duplicate articles using EndNote (n=600, Appendix Exhibit 3 (figure)).

Study selection. We restricted our search to human studies published from January 1, 1990 to August 1, 2017. During title and abstract review, we excluded literature that was not written in English, conference and meeting abstracts, non-research studies (e.g., commentaries, editorials, literature reviews), epidemiological and molecular studies describing genetic risk factors of disease, and studies that examined genetic testing of probands only (Appendix Exhibit 4 (table)). While literature reviews were not included in our review, we reviewed their reference lists and included relevant articles.

Data extraction and synthesis. During full-text review, additional articles were excluded that did not meet our inclusion criteria. We coded included articles using the PICOTS framework(2, 3), which includes abstracting information on each study's population, intervention (if applicable), comparison group (if applicable), outcomes, timing, and setting (Appendix Exhibit 5 (table)). Multiple coders reviewed and abstracted articles, and 20% of included articles were double coded to ensure consistency across coders. When inconsistencies in coding were identified, a third author adjudicated the discrepancy (coding agreement= 86.4%). Given the significant heterogeneity among populations, study designs, outcomes, timing and settings, we did not conduct meta-analyses. We summarized the literature using the following key questions: What interventions have been tested and found effective? What are the barriers and facilitators to cascade screening? What are the considerations when aligning intervention approaches with state and federal privacy policy? Where do we need additional research?

State policy search. In a separate search, we examined laws across the 50 states and the District of Columbia, about laws regulating collection, use and release of genetic information that could affect implementation of some cascade screening approaches.(4, 5) Smith et al. completed a survey of genetic privacy laws across all 50 states which formed the basis for this policy search.(5) We confirmed the effective dates of the laws cited in Smith et al. to determine whether they were still current and relevant to our work. To this end, we conducted a search of the Westlaw database for state statutes and regulations related to health information privacy, genetic testing and genetic privacy, and reportable diseases. We determined when each law cited in Smith et al. was last amended. We found that 77 of the laws had been amended between January 1, 2011 and October 26, 2017, and we included the amended language in our

review. We excluded 224 laws that did not pertain to the disclosure of protected genetic health information. The remaining 46 laws were qualitatively described.

Appendix Exhibit 2. Search strategies employed for each database.

A scoping literature search was systematically conducted to find the literature related to cascade screening and the following areas:

- National health systems
- Barriers and facilitators
- Implementation
- Policy
- Cost effectiveness

We implemented targeted search strategies for each database and topic area (i.e., Medline, Embase, Global Health, PsycInfo, CINHALL, and Scopus. See specific search strategies for each key area below.

Limits: Humans, English, 1990-present

NATIONAL HEALTH SYSTEMS Search Strategy:

Database	Strategy	Run Date	Records
Medline (Ovid) 1946-	<p>(cascade adj3 (screen* OR test*).ti,ab.</p> <p>OR</p> <p>(</p> <p>(((family OR familial OR families OR relatives) adj3 (screen* OR test* OR notify OR notifies OR notification* OR network OR privacy)).ti,ab.)</p> <p>AND</p> <p>(((gene OR genetic* OR genomic*) adj3 (screen* OR test*).ti,ab. OR *Genetic Testing/)</p> <p>)</p> <p>AND</p> <p>(health system OR health systems OR registries OR registry OR national health program* OR national health service*).ti,ab. OR exp National Health Programs/</p> <p>Limits: English, 1990-present</p> <p>Exclude: letters, comments, editorials, biographies, autobiographies</p>	8/1/2017	92 articles

<p>Embase (Ovid) 1947-</p>	<p>(cascade adj3 (screen* OR test*)).ti,ab.</p> <p>OR</p> <p>((((family OR familial OR families OR relatives) adj3 (screen* OR test* OR notify OR notifies OR notification* OR network OR privacy)).ti,ab.) AND (((gene OR genetic* OR genomic*) adj3 (screen* OR test*)).ti,ab. OR *Genetic Testing/)</p> <p>AND</p> <p>(health system OR health systems OR registries OR registry OR national health program* OR national health service*).ti,ab.</p> <p>Limits: English, 1990-present Exclude: letters, comments, editorials, biographies, autobiographies</p>	<p>8/1/2017</p>	<p>146 articles</p>
<p>Global Health (Ovid) 1910-</p>	<p>(cascade adj3 (screen* OR test*)).ti,ab.</p> <p>OR</p> <p>((((family OR familial OR families OR relatives) adj3 (screen* OR test* OR notify OR notifies OR notification* OR network OR privacy)).ti,ab.) AND (((gene OR genetic* OR genomic*) adj3 (screen* OR test*)).ti,ab.)</p> <p>AND</p> <p>(health system OR health systems OR registries OR registry OR national health program* OR national health service*).ti,ab.</p> <p>Limits: English, 1990-present Exclude: letters, comments, editorials, biographies, autobiographies</p>	<p>8/1/2017</p>	<p>7 articles</p>

PsycInfo (Ovid) 1806-	<p>(cascade adj3 (screen* OR test*)).ti,ab.</p> <p>OR</p> <p>((((family OR familial OR families OR relatives) adj3 (screen* OR test* OR notify OR notifies OR notification* OR network OR privacy)).ti,ab.) AND (((gene OR genetic* OR genomic*) adj3 (screen* OR test*)).ti,ab. OR *Genetic Testing/) AND (health system OR health systems OR registries OR registry OR national health program* OR national health service*).ti,ab.</p> <p>Limits: English, 1990-present Exclude: letters, comments, editorials, biographies, autobiographies</p>	8/1/2017	2 articles
CINAHL (Ebsco)	<p>cascade W3 (screen* OR test*)</p> <p>OR</p> <p>(((family OR familial OR families OR relatives) W3 (screen* OR test* OR notify OR notifies OR notification* OR network OR privacy)) AND ((gene OR genetic* OR genomic*) W3 (screen* OR test*))) AND "health system" OR "health systems" OR registries OR registry OR "national health program" OR "national health service" OR (MH "National Health Programs+")</p> <p>Limits: English, peer-reviewed, 1990-present Exclude: letters, comments, editorials, biographies, autobiographies</p>	8/1/2017	6 articles
Scopus 1960-	<p>TITLE-ABS (cascade W/3 (screening OR testing))</p> <p>AND</p> <p>TITLE-ABS("health system" OR "health systems" OR registries OR registry OR "national health program" OR "national health service")</p> <p>Limits: English, peer-reviewed, 1990-present Exclude: letters, comments, editorials, biographies, autobiographies</p>	8/1/2017	21 articles
		De-duplicated in EndNote:	161 articles

BARRIERS AND FACILITATORS Search Strategy:

Database	Strategy	Run Date	Records
Medline (Ovid) 1946-	<p>(cascade adj3 (screen* OR test*)).ti,ab.</p> <p>OR</p> <p>((((family OR familial OR families OR relatives) adj3 (screen* OR test* OR notify OR notifies OR notification* OR network OR privacy)).ti,ab.) AND (((gene OR genetic* OR genomic*) adj3 (screen* OR test*)).ti,ab. OR *Genetic Testing/))</p> <p>AND</p> <p>(barriers OR facilitators).ti,ab.</p> <p>Limits: English, 1990-present Exclude: letters, comments, editorials, biographies, autobiographies</p>	7/27/17	35 articles
Embase (Ovid) 1947-	<p>(cascade adj3 (screen* OR test*)).ti,ab.</p> <p>OR</p> <p>((((family OR familial OR families OR relatives) adj3 (screen* OR test* OR notify OR notifies OR notification* OR network OR privacy)).ti,ab.) AND (((gene OR genetic* OR genomic*) adj3 (screen* OR test*)).ti,ab. OR *genetic screening/))</p> <p>AND</p> <p>(barriers OR facilitators).ti,ab.</p> <p>Limits: English, 1990-present Exclude: letters, comments, editorials, biographies, autobiographies</p>	7/27/2017	60 articles

<p>Global Health (Ovid) 1910-</p>	<p>(cascade adj3 (screen* OR test*)),ti,ab.</p> <p>OR</p> <p>((((family OR familial OR families OR relatives) adj3 (screen* OR test* OR notify OR notifies OR notification* OR network OR privacy)),ti,ab.) AND (((gene OR genetic* OR genomic*) adj3 (screen* OR test*)),ti,ab.))</p> <p>AND</p> <p>(barriers OR facilitators).ti,ab.</p> <p>Limits: English, 1990-present Exclude: letters, comments, editorials, biographies, autobiographies</p>	<p>7/27/2017</p>	<p>6 articles</p>
<p>PsycInfo (Ovid) 1806-</p>	<p>(cascade adj3 (screen* OR test*)),ti,ab.</p> <p>OR</p> <p>((((family OR familial OR families OR relatives) adj3 (screen* OR test* OR notify OR notifies OR notification* OR network OR privacy)),ti,ab.) AND (((gene OR genetic* OR genomic*) adj3 (screen* OR test*)),ti,ab. OR *Genetic Testing/)</p> <p>AND</p> <p>(barriers OR facilitators).ti,ab.</p> <p>Limits: English, 1990-present Exclude: letters, comments, editorials, biographies, autobiographies</p>	<p>7/27/2017</p>	<p>3 articles</p>

CINAHL (Ebsco)	<p>cascade W3 (screen* OR test*)</p> <p>OR</p> <p>(((family OR familial OR families OR relatives) W3 (screen* OR test* OR notify OR notifies OR notification* OR network OR privacy)) AND ((gene OR genetic* OR genomic*) W3 (screen* OR test*)))</p> <p>AND</p> <p>(barriers OR facilitators)</p> <p>Limits: English, peer-reviewed, 1990-present Exclude: letters, comments, editorials, biographies, autobiographies</p>	7/27/2017	2 articles
Scopus 1960-	<p>(TITLE-ABS (cascade W/3 (screening OR testing)) AND TITLE- ABS (barriers OR facilitators))</p> <p>Limits: English, peer-reviewed, 1990-present Exclude: letters, comments, editorials, biographies, autobiographies</p>	7/27/2017	15 articles
		De-duplicated in EndNote:	60 articles

IMPLEMENTATION Search Strategy:

Database	Strategy	Run Date	Records
Medline (Ovid) 1946-	<p>(cascade adj3 (screen* OR test*)).ti,ab.</p> <p>OR</p> <p>((((family OR familial OR families OR relatives) adj3 (screen* OR test* OR notify OR notifies OR notification* OR network OR privacy)).ti,ab.) AND (((gene OR genetic* OR genomic*) adj3 (screen* OR test*)).ti,ab. OR *Genetic Testing/)</p> <p>AND</p> <p>(implementation).ti,ab.</p> <p>Limits: English, 1990-present Exclude: letters, comments, editorials, biographies, autobiographies</p>	7/27/17	63 articles

<p>Embase (Ovid) 1947-</p>	<p>(cascade adj3 (screen* OR test*)).ti,ab.</p> <p>OR</p> <p>((((family OR familial OR families OR relatives) adj3 (screen* OR test* OR notify OR notifies OR notification* OR network OR privacy)).ti,ab.) AND (((gene OR genetic* OR genomic*) adj3 (screen* OR test*)).ti,ab. OR *genetic screening/))</p> <p>AND</p> <p>(implementation).ti,ab.</p> <p>Limits: English, 1990-present Exclude: letters, comments, editorials, biographies, autobiographies</p>	<p>7/27/2017</p>	<p>81 articles</p>
<p>Global Health (Ovid) 1910-</p>	<p>(cascade adj3 (screen* OR test*)).ti,ab.</p> <p>OR</p> <p>((((family OR familial OR families OR relatives) adj3 (screen* OR test* OR notify OR notifies OR notification* OR network OR privacy)).ti,ab.) AND (((gene OR genetic* OR genomic*) adj3 (screen* OR test*)).ti,ab.))</p> <p>AND</p> <p>(implementation).ti,ab.</p> <p>Limits: English, 1990-present Exclude: letters, comments, editorials, biographies, autobiographies</p>	<p>7/27/2017</p>	<p>8 articles</p>

PsycInfo (Ovid) 1806-	<p>(cascade adj3 (screen* OR test*)),ti,ab.</p> <p>OR</p> <p>((((family OR familial OR families OR relatives) adj3 (screen* OR test* OR notify OR notifies OR notification* OR network OR privacy)),ti,ab.) AND (((gene OR genetic* OR genomic*) adj3 (screen* OR test*)),ti,ab. OR *Genetic Testing/)</p> <p>AND</p> <p>(implementation).ti,ab.</p> <p>Limits: English, 1990-present Exclude: letters, comments, editorials, biographies, autobiographies</p>	7/27/2017	3 articles
CINAHL (Ebsco)	<p>cascade W3 (screen* OR test*)</p> <p>OR</p> <p>(((family OR familial OR families OR relatives) W3 (screen* OR test* OR notify OR notifies OR notification* OR network OR privacy)) AND ((gene OR genetic* OR genomic*) W3 (screen* OR test*)))</p> <p>AND</p> <p>(implementation)</p> <p>Limits: English, peer-reviewed, 1990-present Exclude: letters, comments, editorials, biographies, autobiographies</p>	7/27/2017	5 articles
Scopus 1960-	<p>(TITLE-ABS (cascade W/3 (screening OR testing)) AND TITLE-ABS (implementation))</p> <p>Limits: English, peer-reviewed, 1990-present Exclude: letters, comments, editorials, biographies, autobiographies</p>	7/27/2017	33 articles
		De-duplicated in EndNote:	97 articles

POLICY Search Strategy:

Database	Strategy	Run Date	Records
Medline (Ovid) 1946-	<p>(cascade adj3 (screen* OR test*).ti,ab.</p> <p>OR</p> <p>(</p> <p>(((family OR familial OR families OR relatives) adj3 (screen* OR test* OR notify OR notifies OR notification* OR network OR privacy)).ti,ab.)</p> <p>AND</p> <p>(((gene OR genetic* OR genomic*) adj3 (screen* OR test*).ti,ab. OR *Genetic Testing/)</p> <p>)</p> <p>AND</p> <p>(policy OR policies OR legislation OR laws OR legislation OR privacy OR lawsuit* OR statutes OR jurisprudence OR civil suits OR litigation OR government regulation).ti,ab. OR exp *Legislation as Topic/</p> <p>Limits: English, 1990-present</p> <p>Exclude: letters, comments, editorials, biographies, autobiographies</p>	7/27/17	68 articles
Embase (Ovid) 1947-	<p>(cascade adj3 (screen* OR test*).ti,ab.</p> <p>OR</p> <p>(</p> <p>(((family OR familial OR families OR relatives) adj3 (screen* OR test* OR notify OR notifies OR notification* OR network OR privacy)).ti,ab.)</p> <p>AND</p> <p>(((gene OR genetic* OR genomic*) adj3 (screen* OR test*).ti,ab. OR *genetic screening/)</p> <p>)</p> <p>AND</p> <p>(policy OR policies OR legislation OR laws OR legislation OR privacy OR lawsuit* OR statutes OR jurisprudence OR civil suits OR litigation OR government regulation).ti,ab.</p> <p>Limits: English, 1990-present</p> <p>Exclude: letters, comments, editorials, biographies, autobiographies</p>	7/27/2017	78 articles

<p>Global Health (Ovid) 1910-</p>	<p>(cascade adj3 (screen* OR test*).ti,ab. OR ((((family OR familial OR families OR relatives) adj3 (screen* OR test* OR notify OR notifies OR notification* OR network OR privacy)).ti,ab.) AND (((gene OR genetic* OR genomic*) adj3 (screen* OR test*).ti,ab.)) AND (policy OR policies OR legislation OR laws OR legislation OR privacy OR lawsuit* OR statutes OR jurisprudence OR civil suits OR litigation OR government regulation).ti,ab. Limits: English, 1990-present Exclude: letters, comments, editorials, biographies, autobiographies</p>	<p>7/27/2017</p>	<p>4 articles</p>
<p>PsycInfo (Ovid) 1806-</p>	<p>(cascade adj3 (screen* OR test*).ti,ab. OR ((((family OR familial OR families OR relatives) adj3 (screen* OR test* OR notify OR notifies OR notification* OR network OR privacy)).ti,ab.) AND (((gene OR genetic* OR genomic*) adj3 (screen* OR test*).ti,ab. OR *Genetic Testing/) AND (policy OR policies OR legislation OR laws OR legislation OR privacy OR lawsuit* OR statutes OR jurisprudence OR civil suits OR litigation OR government regulation).ti,ab. Limits: English, 1990-present Exclude: letters, comments, editorials, biographies, autobiographies</p>	<p>7/27/2017</p>	<p>11 articles</p>

CINAHL (Ebsco)	<p>cascade W3 (screen* OR test*)</p> <p>OR</p> <p>(((family OR familial OR families OR relatives) W3 (screen* OR test* OR notify OR notifies OR notification* OR network OR privacy)) AND ((gene OR genetic* OR genomic*) W3 (screen* OR test*)))</p> <p>AND</p> <p>(policy OR policies OR legislation OR laws OR legislation OR privacy OR lawsuit* OR statutes OR jurisprudence OR civil suits OR litigation OR government regulation)</p> <p>Limits: English, peer-reviewed, 1990-present Exclude: letters, comments, editorials, biographies, autobiographies</p>	7/27/2017	14 articles
Scopus 1960-	<p>(TITLE-ABS (cascade W/3 (screening OR testing)) AND TITLE-ABS (policy OR policies OR legislation OR laws OR legislation OR privacy OR lawsuit OR statutes OR jurisprudence OR "civil suits" OR litigation OR "government regulation"))</p> <p>Limits: English, peer-reviewed, 1990-present Exclude: letters, comments, editorials, biographies, autobiographies</p>	7/27/2017	15 articles
		De-duplicated in EndNote:	100 articles

COST EFFECTIVENESS Search Strategy:

Database	Strategy	Run Date	Records
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<p>Medline (Ovid) 1946-</p>	<p>(cascade adj3 (screen* OR test*)).ti,ab.</p> <p>OR</p> <p>((((family OR familial OR families OR relatives) adj3 (screen* OR test* OR notify OR notifies OR notification* OR network OR privacy)).ti,ab.) AND (((gene OR genetic* OR genomic*) adj3 (screen* OR test*)).ti,ab. OR *Genetic Testing/)</p> <p>AND</p> <p>exp *"Costs and Cost Analysis"/ OR (costs OR cost effective*).ti,ab.</p> <p>Limits: English, 1990-present Exclude: letters, comments, editorials, biographies, autobiographies</p>	<p>8/1/2017</p>	<p>166 articles</p>
<p>Embase (Ovid) 1947-</p>	<p>(cascade adj3 (screen* OR test*)).ti,ab.</p> <p>OR</p> <p>((((family OR familial OR families OR relatives) adj3 (screen* OR test* OR notify OR notifies OR notification* OR network OR privacy)).ti,ab.) AND (((gene OR genetic* OR genomic*) adj3 (screen* OR test*)).ti,ab. OR *genetic screening/)</p> <p>AND</p> <p>exp "cost benefit analysis"/ or "cost effectiveness analysis"/ OR (costs OR cost effective*).ti,ab.</p> <p>Limits: English, 1990-present Exclude: letters, comments, editorials, biographies, autobiographies</p>	<p>8/1/2017</p>	<p>263 articles</p>

<p>Global Health (Ovid) 1910-</p>	<p>(cascade adj3 (screen* OR test*)).ti,ab. OR ((((family OR familial OR families OR relatives) adj3 (screen* OR test* OR notify OR notifies OR notification* OR network OR privacy)).ti,ab.) AND (((gene OR genetic* OR genomic*) adj3 (screen* OR test*)).ti,ab.)) AND (costs OR cost effective*).ti,ab. OR "cost benefit analysis"/ or "cost effectiveness analysis"/ Limits: English, 1990-present Exclude: letters, comments, editorials, biographies, autobiographies</p>	<p>8/1/2017</p>	<p>14 articles</p>
<p>PsycInfo (Ovid) 1806-</p>	<p>(cascade adj3 (screen* OR test*)).ti,ab. OR ((((family OR familial OR families OR relatives) adj3 (screen* OR test* OR notify OR notifies OR notification* OR network OR privacy)).ti,ab.) AND (((gene OR genetic* OR genomic*) adj3 (screen* OR test*)).ti,ab. OR *Genetic Testing/) AND exp *"Costs and Cost Analysis"/ OR (costs OR cost effective*).ti,ab. Limits: English, 1990-present Exclude: letters, comments, editorials, biographies, autobiographies</p>	<p>8/1/2017</p>	<p>5 articles</p>

CINAHL (Ebsco)	<p>cascade W3 (screen* OR test*)</p> <p>OR</p> <p>(((family OR familial OR families OR relatives) W3 (screen* OR test* OR notify OR notifies OR notification* OR network OR privacy)) AND ((gene OR genetic* OR genomic*) W3 (screen* OR test*)))</p> <p>AND</p> <p>(costs OR cost effective*) OR (MH "Cost Benefit Analysis")</p> <p>Limits: English, peer-reviewed, 1990-present Exclude: letters, comments, editorials, biographies, autobiographies</p>	8/1/2017	20 articles
Scopus 1960-	<p>(TITLE-ABS (cascade W/3 (screening OR testing)) AND TITLE- ABS ("cost benefit" OR "cost effective" OR "cost effectiveness"))</p> <p>Limits: English, peer-reviewed, 1990-present Exclude: letters, comments, editorials, biographies, autobiographies</p>	8/1/2017	67 articles
		De-duplicated in EndNote:	278 articles

Exhibit 3 (figure). PRISMA flow diagram for full-text inclusion (2). *Reference lists from relevant literature reviews were examined and abstracts for citations related to cascade screening were included.

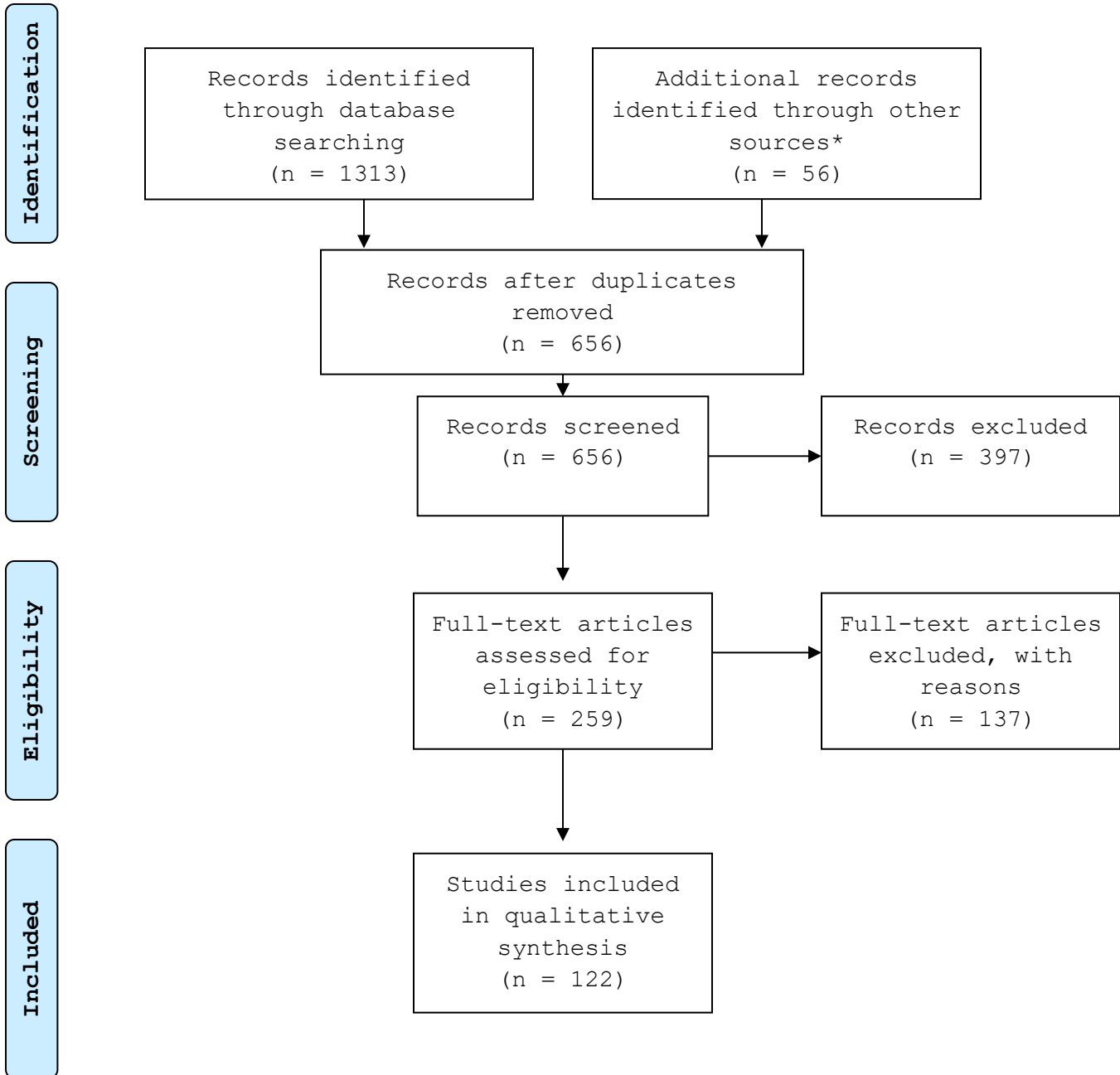


Exhibit 4 (table). Inclusion and exclusion criteria for literature from January 1990-August 2017.

Inclusion	Exclusion
<ul style="list-style-type: none"> • All countries • 1990-present • All articles about cascade screening (especially effectiveness, cost-effectiveness, comparative effectiveness, interventions, policy, barriers and facilitators) • Policy analyses (with methods and results section) • Human studies • References in Literature Reviews related to cascade screening or family communication • Study of probands communication to family members about genetic testing 	<ul style="list-style-type: none"> • Non-English written • Not a research study (no methods and/or results section) • Literature reviews • Epidemiological studies describing the association between polymorphisms and disease • Mechanism of action studies • Commentaries • Editorials • Proof of concept/validation for genetic screening technologies or risk models • Abstract or poster only • Clinical guidelines • Not focused on genetic testing of family members

Exhibit 5 (table). Codebook used for full-text data abstraction.

PICOTS	Abstraction Field	Description
Pre-populated	First Author Title DOI PMID PMCID	
Include?	Include full-text? If exclude, why?	Yes/No Free text; Write if excluded study is about: Proband testing only, policy analyses, registry, literature review, guideline; IF EXCLUDED, NO ADDITIONAL FIELDS NEED TO BE EXTRACTED
Year of publication	XXXX	Year that the article was published
Population	Study population Total sample size White (n) Asian (n) Black (n) Hispanic (n) Male (n) Pediatric (n) Other	Patient/Proband, Family Member, Provider, Healthcare Administrator, Multiple stake-holder, Other blank if not reported or calculated in paper blank if not reported or calculated in paper blank if not reported or calculated in paper blank if not reported or calculated in paper blank if not reported or calculated in paper blank if not reported or calculated in paper blank if not reported or calculated in paper was another race/ethnicity reported? If so, name here; otherwise leave blank
Intervention	Study/Intervention design	Comparative Effectiveness (comparing more than one intervention), Randomized control trial (randomize study participants to control/intervention groups), Qualitative (e.g., interviews and/or focus groups ONLY, does not include quantitative regression models), Pre/Post Study (no comparator group, compares outcomes before and after an intervention), Cohort (longitudinal—studies a group of participants overtime points), Cross-sectional (data collected at one

	<p>Is there an intervention?</p> <p>Who delivers the intervention?</p> <p>If Provider delivers intervention, what type?</p> <p>If Registry, what type?</p> <p>If Registry, what type?</p> <p>If Resources are Included in intervention, what kind?</p> <p>Resources available to public?</p> <p>Was the intervention successful?</p>	<p>point in time), Simulation modeling (e.g., Cost analyses, cost effectiveness, Markov Models, Decision analysis), Mixed methods (e.g., qualitative AND quantitative data are used), Multiple (e.g., cross-sectional analyses and simulation modeling), other</p> <p>Yes/No</p> <p>Provider Initiated, Proband Initiated, Family Initiated, Research team initiated, Disease Specific non-profit (e.g., FH Foundation), Multiple, Other; LEAVE BLANK IF NO INTERVENTION</p> <p>Nurse, Genetics Provider, Primary Care/Family Doctor, Specialist (e.g., oncologist, cardiologist or iridologist), Community Health/public health Worker (e.g., department of health), Other, Multiple; LEAVE BLANK IF NO INTERVENTION</p> <p>Clinic, State, Multi-State, National, International, Other; LEAVE BLANK IF NO REGISTRY</p> <p>Health system (e.g., Geisinger, Kaiser, hospital-based), Non-profit (e.g., FH Foundation), public health (e.g., health department), Other; LEAVE BLANK IF NO REGISTRY</p> <p>Written educational material, Online educational material, Draft letters/email, Counseling session by genetics provider, Counseling session by other provider, Online or video counseling session, Other, Multiple; LEAVE BLANK IF NO RESOURCES</p> <p>Yes/No/Unsure (no need to look up, only mark yes or no if obvious from article); LEAVE BLANK IF NO RESOURCES</p> <p>Yes, Only partially effective, No, Unclear; LEAVE BLANK IF NO INTERVENTION</p>
Comparator	What type of comparator group?	Comparing to a healthy population, Comparing to the standard of care (usual care), Comparing to another intervention, Other, None
Outcomes	<p>Feasibility</p> <p>Fidelity</p> <p>Penetration/reach</p>	<p>Yes/No</p> <p>Yes/No</p> <p>Yes/No</p>

	Acceptability Sustainability Uptake Costs Efficiency Safety Equity Timeliness Barriers/Facilitators/ Patient Centeredness Knowledge Health outcomes (mental/physical/psycho- social/behavioral) Satisfaction	Yes/No Yes/No Yes/No Yes/No Yes/No Yes/No Yes/No Yes/No Yes/No Yes/No Yes/No Yes/No Yes/No Yes/No
Timing	Year(s) of data collection (XXXX-XXXX) or (XXXX)	(XXXX-XXXX, XXXX)
Setting	Country Setting/Source of study population (if non-intervention)	United States, Non-US Study, Both Clinical (academic), Clinical (non-academic), Clinical (unsure if academic/non-academic), Public Health (e.g., registry), Other (e.g., online/web)

Exhibit 6 (table). Characteristics of included studies (n=122).

Domain	Study Characteristics	%	n	‡References
Population	Reported Race/Ethnicity of Study Population*	25.8	22	2,4,7,10-11,17,19, 21,29,34,40,50,54, 57,64,66-68,97,106, 112,116
	<i>Majority non-Hispanic white population</i>	80.0	17	2,4,7,10-11,17,19, 21,29,40,50,54, 57, 66-68, 106,112,116
	Included Pediatrics (<18 years)	3.3	4	71,88,105,115
Intervention	Assessed an Intervention**	22.1	27	2,9,14,27,31,35, 37,39-40,46,66,68, 71,78,87-88,90,92,97, 99,107,108,110-112, 114,122
	Intervention Included a Comparator Group	25.9	7	46,71,78,88,108, 110,122
	<i>Standard of care comparator</i>	3.7	1	46
	<i>Compared to another intervention</i>	14.8	4	78,88,110,122
	<i>Other comparator (e.g., other disease)</i>	7.4	2	71,108
Study Design	Simulation Modeling/Cost Analysis	31.1	38	1,6,12-13,18,22-24,26,28,32,45,48, 55,59-61,64,69-70,72-73,77,80-85,89,91,95,100-103,120-121
	Cross-sectional	28.7	35	3,4,8-10,14, 19,21,25, 27,29-30,33-36,38-39,50,52,63,74,93-94,96,98,104-105,109,113,115, 117-118,122
	Cohort/longitudinal	17.2	21	31,37,40-41,43,53,58,66,68, 71,79,87,90,92,97,106-108,110-111, 114
	Qualitative	13.1	16	5,7,11,15-16,42,44,47,49,54,56-57,62,86,112,119
	Mixed Methods	8.2	10	17,20,51,65,67,75-76,88,99,116
	Randomized Controlled Trial	1.6	2	46,78
Outcomes Measured	Feasibility	15.6	19	4,9,14,20,24,27,31, 39,43,45,71,72,81,87-88,96,102-103,115
	Fidelity	1.6	2	12,55
	Penetration/reach	5.7	7	45,60,90,100,103, 106,121
	Acceptability	18.0	22	2,9,16,22,39-40,42-43,54,56,61,72,74,81, 84,88,96,102-103,107,112,121
	Sustainability	1.6	2	45,71
	Uptake	27.9	34	6-7,10-11,19,25,29,34-38,40-41,46,53-54,58,66-67,74-76,79,88,92-93,96-97,105,107-108,110-111

Costs	32.0	39	1,6,12-13,18,22-24,26,28,32,37,39,45, 48,55,59-61,64,68-70,72-73,82-85,87,89,91,95,100-103,120-121
Efficiency	12.3	15	23,45,60-61,64-65,82,84,87,91,95,102-103,107,121
Safety	1.6	2	45,86
Equity	1.6	2	7,16
Timeliness	7.4	9	19,37,39,77,84,87, 100,116,121
Barriers/Facilitators/Patient Centeredness	27.0	33	5,7,10-11,16,19-20,25,35-36,40-42,44,49,54,56-57,66,74-75,78,87-88,92,96,99,112-113,116-118,122
Health outcomes (mental/physical/psychosocial)	41.8	51	1,11,16,18-19,22-25,27,31,37-38,40,45-48,50,55,60,64,66,68-69,72,77,80-82,84,90-91,95,99-100,102-107,109-111,114-115,119-122
Knowledge	31.1	38	2-3,5,7-8,11,13-15,17,19-21,25, 30,33-34,36,40, 44,49-50,54,56,57, 61-62,68,74-75,88,96,98-99,103,112,116,122
Satisfaction	11.5	14	2-3,9,19,27,37,52,56-57,68,87-88,103,122
Timing	See Exhibit 2 (figure).		
Setting			
US	28.7	35	10,12,15,17,20-21, 27-30,32-35,40,43, 50,54,57-58,61-63,66-68,78,82,86,91,93,98, 105,116,119
Non-US	69.7	85	1-9,13-14,16,18-19,22-26,31,37-39,41-42,44-49,51-53,55-56,59-60,64-65,69-77,79-81,83-85,87-90,92,94-97,99-104,106-115,117-118,120-122
Both	1.6	2	11,36

*Among non-simulation modeling studies only (n=84); **Not including simulation modeling studies; ‡See Appendix Exhibit 7 for references

Exhibit 7. References for all included articles (n=122).

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Exhibit 8 (table). State-level genetic disclosure policies by state.

Genetic Disclosure Laws by State		Patient Consent			Exceptions						
State	Statute	Access Genetic Information	Disclose Genetic Information	Required for	Registries	Registries if de-identified	Research	Research if de-identified	Any purpose if de-identified	Diagnosis	Notes
Alabama											
Alaska	Alaska Stat. § 18.13.010	X	X	Any Person							
Arizona	Ariz. Rev. Stat. § 12-2801 et. seq.	X	X	Any Person	X					X	
Arkansas	Ark. Code Ann. § 20-35-101 et. seq.		X	Any Person				X			
California	Cal. Civ. Code § 56.17		X	Any Person				*	*		
	Cal. Ins. Code § 10123.35		X	Any Person							
	Cal. Ins. Code § 10140.1		X	Any Person							
	Cal. Ins. Code § 10146 et. seq.		*	Health Insurers						X	
Colorado	Colo. Rev. Stat. § 10-3-1104.6		X	Any Person				X	*	X	
Connecticut	Conn. Gen. Stat. § 38a-988 & 38a-988a		X	Health Insurers				X			Disclosure consent needed for marketing purposes
Delaware	Del. Code tit. 16, § 1201 et seq.	X	X	Any Person				X			
District of Columbia											
Florida	Fla. Stat. § 760.40		X	Any Person							

Georgia	Ga. Code Ann. § 33-54-2 et seq.	X	X	Any Person				X			
Hawaii	Haw. Rev. Stat. § 431:10A-118		X	Health Insurers							
Idaho											
Illinois											
Indiana	Ind. Code § 16-18-2-168; 16-39-1-4, -5-3		X	Healthcare Providers				X			
Iowa	Iowa Code § 729.6	X	X	Any Person		X	X				
Kansas											
Kentucky	Ky. Rev. Stat. Ann. § 304.12-085		X	Health Insurers							
Louisiana	La. Rev. Stat. § 22:1023	X	*	Any Person							
Maine											
Maryland	Md. Code Ann., Ins. § 27-909		X	Health Insurers & Healthcare Providers				*	*		
Massachusetts	Mass. Gen. Laws ch. 111, § 70G		X	Health Insurers & Healthcare Providers				X		X	
Michigan	Mich. Comp. Laws § 333.17020	X	X	Health Insurers & Healthcare Providers							
	Mich. Comp. Laws § 333.17520	X	X	Health Insurers & Healthcare Providers							
Minnesota	Minn. Stat. § 13.386		X	Government Entities							
	Minn. Stat. § 144.295							X			
Mississippi											
Missouri	Mo. Rev Stat § 375.1309		X	Any Person				X			
Montana											

Nebraska	Neb. Rev. Stat. § 71-551	*	*	Healthcare Providers							Applies only to physicians ordering predictive genetic tests
Nevada	Nev. Rev. Stat. § 629.101 et seq.	X	X	Any Person				X			
New Hampshire	N.H. Rev. Stat. Ann. § 141-H:1 et seq.		X	Any Person							
New Jersey	N.J. Stat. Ann. § 10:5-5, 10:5-43 et seq.	X	X	Any Person				X		X	
New Mexico	N.M. Stat. § 24-21-1 et seq.		X	Any Person				X	*		
New York	N.Y. Civ. Rights Law § 79-l		X	Any Person except Health Insurers				X			
North Carolina											
North Dakota											
Ohio	Ohio Rev. Code Ann. § 3904.01, .13		X	Health Insurers				X		*	
Oklahoma	Okla. Stat. tit. 36, § 3614.3-4		X	Any Person except Health Insurers				X			
Oregon	Or. Rev. Stat. § 192.531 et seq.	X	X	Any Person		X		X			
Pennsylvania											
Rhode Island	R.I. Gen. Laws § 1956-27-18-52, 52.1	X	X	Health Insurers				X			
	R.I. Gen. Laws § 1956-27-19-44, 44.1	X	X	Health Insurers				X			Applies to non-profit hospitals that offer insurance

	R.I. Gen. Laws § 1956 27-20-39, 39.1	X	X	Health Insurers				X			Applies to non-profit medical service organizations that offer insurance
South Carolina	S.C. Code Ann. § 1976 38-93-10 et seq.	X	X	Health Insurers				*	*	X	
South Dakota	S.D. Codified Laws § 34-14-21 et seq.	X	*	Any Person							
Tennessee	Tenn. Code Ann. § 56-7-2701 et seq.	*	X	Health Insurers							
Texas	Tex. Ins. Code Ann. § 546.001		X	Health Insurers				X			
Utah											
Vermont	Vt. Stat. Ann. Tit. 18, § 9331 et seq.	X	X	Any Person				X			
Virginia											
Washington	Wash. Rev. Code § 70.02.010 et seq.		X	Healthcare Providers							
West Virginia	W. Va. Code § 16-29-1		*	Any Person							
Wisconsin	Wis. Stat. § 146.82		X	Any Person							
Wyoming	Wyo. Stat. Ann. § 14-2-710	*	*	Any Person				*	*		

Key: An X indicates that the statement, prohibition (or whatever the category is) is explicit. * indicates that the statement is implied

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