

Codebook MCA "Predictive Genetic Testing"

Search algorithms

German

(((*Angelina* or *Jolie*) AND (genet* OR Gen OR BRCA* OR Mastektomie or Eierstöcke or Eierstock OR Effekt*)) * OR BRCA* OR Gentest* OR genetisch* Test* OR genetisch* Test OR Lynch-Syndrom* OR Lynch Syndrom* OR ((personalisiert* Medizin OR personalisiert* Gesundheit) AND genet*) OR (((prädiktiv* OR präventiv*) AND (genet* OR genom* OR genome)) OR genet* Veranlagung* OR Prädisposition) AND *test*)

English

(((*Angelina* or *Jolie*) AND (genet* OR gene OR effect* OR BRCA* OR mastectomy or ovar*)) OR BRCA* OR gene* test* OR Lynch syndrom* OR ((personalised medicine OR personalised health) AND (genet* or genom*)) OR (((predictive OR preventive) AND (genet* OR genom*)) OR genetic* predispos*) AND test*)

Inclusion and exclusion criteria of articles

Inclusion criteria

The topic **predictive genetic or genomic testing on born humans** OR its consequences (i.e. preventive surgery) OR its social/economical/political implications is the main focus or at least one of the key points in the article (key point meaning that at least 1/5 of article is focusing on PGT).

- Including direct-to-consumer genetic testing when implicitly or explicitly about predictive genetic testing (assumed is mostly the case)
- Including gene patenting, if about predictive tests and their consequences
- Including genetic screening, when predictive (but not screening of embryos or unborn babies)

Exclusion criteria

Nothing to do with predictive genetic or genomic testing, especially:

1. Prenatal/preimplantation genetic testing
2. Genetic testing for diagnostic purposes (diagnose a certain disease, identify cancer subtype etc.)
3. Genetic testing for treatment purposes (i.e. pharmacogenetic testing)
4. Genetic testing on animals, plants
5. Ancestry search/prove
6. Evolutionary genetics (yeti etc.)
7. Forensic purposes (gene tests for crime, identification of bodies...)
8. keywords used in a completely different context (e.g. Film tips)
9. Gene patenting
10. Very short articles (<100 words in main text)
 - Cave: short announcements on front page are included, if the main article is included as well (merge them into one article)
11. Epigenetic tests

Bibliography

Gerhards, Jürgen; Schäfer, Mike S. (2007): Die Herstellung einer öffentlichen Hegemonie: Humangenomforschung in der deutschen und der US-amerikanischen Presse: Springer-Verlag.

Gerhards, Juergen; Schäfer, Mike S. (2009): Two normative models of science in the public sphere. human genome sequencing in German and US mass media. In *Public Understanding of Science* 18 (4), pp. 437–451. DOI: 10.1177/0963662507082891.

O'Mahony, Patrick; Schäfer, Mike Steffen (2005): The 'Book of Life' in the Press Comparing German and Irish Media Discourse on Human Genome Research. In *Social Studies of Science* 35 (1), pp. 99–130. DOI: 10.1177/0306312705046542.

Schäfer, Mike S. (2009): From public understanding to public engagement. An empirical assessment of changes in science coverage. In *Science Communication* 30 (4), pp. 475–505.

Part I Quantitative analysis of newspaper coverage

0 Copy-pasted data

Preliminarily collected during sampling process, excluded from pretest

0-1 Article title (title)

Copy-paste the title of the article

0-2 Keyword(s) (keyword)

Separate by “,” if several in the same article

0-3 No of words in the article (words)

Count the number of words by highlighting title, subtitles, article text, textboxes and subtext of pictures and click “Word Count” under the “Review” category in Microsoft Word. Please note: Even if a word count is already given by the database Factiva, use your own word count, since those are overestimating the real article length.

0-4 Publication date

DD MM YYYY

0-5 Name of medium where article was published

Table mediumName

00	Unclear/unknown	31	Tages-Anzeiger
11	Daily Telegraph	32	Neue Zürcher Zeitung
12	The Guardian	99	Other

0-6 Author

State author of the article

0-7 Newspaper columns (column)

Zeitungsrubrik

0	not applicable	7	Local news
1	Title/front / editorial	8	Other (Sports / Cars / Travel / Others)
2	Politics / Switzerland and the world / national	9	Magazine
3	Feuilleton / Style / Literature / Media / Art / nonfiction / Education / Society / culture	10	News
4	Economics / Business / Finances / Investment / Money	11	Analyse (TA) / Hintergrund / Temps fort
5	Science / Technique	12	International
6	Opinion / reader's letters	13	People
		14	Health
		99	not specified

0-8 Additional front teaser

State if this article had an additional teaser on the front page of the newspaper

0 No 1 Yes

1 Quantitative analysis of newspaper coverage

Article ID

State number assigned to the article (4-digit number)

0xxx-3xxx Switzerland

4xxx UK

Name of coder

- 1 Bettina
- 2 Fabian
- 3 David
- 4 Noah

Date of registration

DD MM YYYY

1-1 Topics covered by article

→ see annexe!

Concerning genetics, what were the **main topic(s)** of the article?

The **main topic** is identified by:

- (1) mentioned in the title
- (2) mentioned in subtitle/lead
- (3) mentioned in the first paragraph
- (4) which focus gets most space (wordcount) in the article.

Additional topics may be coded only if there are additional key aspects in the article that are also **mentioned in title, subtitle, lead or first paragraph AND that take important space (at least 10 full sentences or more than half of the article body)**.

1-2 Topic evaluation throughout article

How were the previously identified topic(s) evaluated in the article? Look at all directive statements i.e., risks/benefit assessments regarding the topic throughout the article. Statements must be explicit. **For certain topics, PGT in general is evaluated → see Topic list in annex, last column!** If the evaluation is uncertain, use evaluations in title, subtitle and lead to make a decision about the overall evaluation.

- 0 Unclear
- 1 **Clearly positive / benefits:** only or for the most part positive arguments / benefits
- 2 **Ambivalent / risks+benefits:** both positive (benefit) and negative (risk) arguments mentioned
- 3 **Clearly negative / risks:** only or for the most part negative arguments / risks
- 4 **Neutral:** no arguments stated
- 9 Not applicable: no topic identified

1-3 Sources/stakeholders

Can be sources (publications, reviews, studies, other articles, newspapers etc.) or stakeholders (individuals or collectives, i.e. persons, groups, committees, parties, organizations, institutions) that are **cited directly or indirectly** in the article and that give **information or opinions** on the topic. An infinite number of sources/stakeholders can be coded. Journalists are only sources/stakeholders if they explicitly state their opinion (e.g. editorial, comment). If a source/stakeholder is only mentioned in the sense that it is info about it, it is not coded (it did not place its own message in the article).

Experts that are made explicit later in the text are coded as the actual person/organization (e.g. "Expert" is mentioned in the title, and later in the text "Dr. XY" is quoted, and it is clear from the context that this Dr. is the expert from the title, then they are merged – Dr. XY consequently gets a "dominant" status because mentioned in title). **Please also code secondary sources (e.g. the New York Times, when mentioned that it published Angelina Jolie's statement).**

1-3.1 Source/stakeholder name

Please state here full name of the stakeholder as it appears in the text (including titles, i.e. Dr., Prof., etc.) or name of institutions (full and abbreviation, if applicable); as well as the source's name/affiliation (not applicable if no source attributed).

1-3.2 Source/stakeholder category

If a person is cited, please code the person as a source (e.g. 21 → Prof. XY, author of research study Z, from University U). If e.g. a publication/study/report is cited code these separately (e.g. 24 → research paper). **If several attributes are connected to one stakeholder (e.g., "die Nationalrätin und Ärztin Yvonne Gilli") code the first attribute as category. The only exception is if the content clearly states otherwise (e.g., if the whole article is about Ärztin Yvonne Gilli, and the fact that she is a politician is merely an artefact mentioned only once).**

→ see annexe!

1-3.3 Is this a secondary source?

A secondary source can be another newspaper (e.g. the New York Times, when mentioned that it published Angelina Jolie's statement); a journal's name where a study that is presented in the article has been published, etc.

For secondary sources, the evaluation is "not applicable"!

- 0 No
- 1 Yes

1-3.4 How predominant was this source/stakeholder in the article

If a stakeholder is coded several times (for several topics) in 1 article, the predominance remains the same!

- 0 Unclear/unknown
- 1 **Dominant:** this source/stakeholder had important space (title, lead, picture headlines/citations (blue text), first paragraph or majority of text) or was the only stakeholder mentioned in this article.
- 2 **Shared:** this source/stakeholder took important and visible space, but others were also present.
- 3 **Minor:** this source/stakeholder was merely mentioned on the side (1 sentence or less).
- 9 Not applicable

1-3.5 Evaluation(s) of topic(s) by source/stakeholder

How were the previously identified topic(s) evaluated by the source/stakeholder? Look at all directive statements of this source/stakeholder throughout the article. Statements must be explicit. (An evaluation is identified if the text passage answers the question "Is the topic good or bad?")

Example: "Shortly after its launch, Time magazine named 23andMe's test the best invention of the year, describing it as one of the most crucial medical breakthroughs in decades." (Daily Telegraph, 11.4.2015) → answers the question "Is DTC good? Yes." by the Time magazine. **For secondary sources, the evaluation is "not applicable"!**

- 0 Unclear
- 1 **Clearly positive / benefits:** only or for the most part positive arguments / benefits
- 2 **Ambivalent / risks+benefits:** both positive (benefit) and negative (risk) arguments mentioned
- 3 **Clearly negative / risks:** only or for the most part negative arguments / risks
- 4 **Neutral:** no arguments stated
- 9 Not applicable: for secondary sources

1-4 Occasion of article¹ (occasion)

Here, the occasion of the article is stated (has nothing to do with the topic), which is connected to the release of the article. The occasion can be in the past, the present or the future and could also be something that did not take place / was postponed. **If several occasions apply, choose the higher ranked one (1=highest priority, 5=lowest priority). To identify the occasion, please screen the article for announcements which indicate what triggered the occasion of the article. In the case of press releases/conferences this can be quite implicit. Example:**

"Gestern hat die Clubleitung die Resultate im Stade Olympique präsentiert" (TagesAnzeiger, 14.12.2013) → press conference

„Die kalifornische Life Technologies Corporation stellte gestern ein Analysegerät vor, mit dem eine vollständige DNA-Untersuchung für rund 1000 Dollar durchgeführt werden kann.“ (TagesAnzeiger, 11.1.2012) → press conference

„A four-year Europe-wide trial was announced on Monday" (The Guardian, 2.6.2015) → press release

"Experts said last night" (The Daily Telegraph, 27.6.2014) → press conference

"... research conducted by Bowel Cancer UK and the Royal College of Pathologists and released on Monday..." (The Guardian, 8.8.16) → press release

There is only one occasion per article.

- a) If there are several mentioned, take the one that is mentioned in the title, subtitle or first in the article.
- b) If there are several actions by one stakeholder that led to the release of the article, code the earlier one.
- c) If a stakeholder A is referring to stakeholder B (e.g., a report is criticizing DTC companies), code the action of stakeholder A (the report: code 2 (if a released report) or 3 (if an internal report))
- 0 No occasion recognizable / not applicable
- 1 **Message placed into mass media:** editorials, comments, letter to the editor written by a stakeholder
- 2 **Mass media directly targeted:** a stakeholder aims to get his message into mass media (press release/conference)
- 3 **Media agenda setting:** the coverage of another medium (newspaper, TV, news agency, magazine, etc.) triggered the release of this article (as initiator, please do not code the other medium here, but the stakeholder who originally initiated the coverage in this other medium)
- 4 **Mass media NOT directly targeted:** there is an occasion, but it is not stated that media were directly targeted (e.g. paper publications, events, incidents) (it is possible that no initiator is recognizable for such an occasion)
- 5 **Case story / interview:** written by a journalist about a special case/person (always code 11 as initiator)
- 9 Other (please specify in comment section)

¹ Adapted from Gerhards, Schäfer 2007.

1-5 Initiator [Veranlasser] of occasion (initiator)

Who was the main initiator of the occasion that led to the article?

If there are several initiators, code the more dominant one; if same dominance, code the first that is mentioned.

If a stakeholder initiates the article via a secondary source (e.g. through another newspaper article that is referred to in this article), do NOT code the secondary source but the original stakeholder that placed his/her message in the media.

No occasion → no initiator

→ See annexe

1-6 Comments of coder (comments)

Please state here any comments, problems or thoughts

Annexe

Topic list

No	Topic	Description	Topic to evaluate
0	Unclear/unknown		
19	Direct-to-consumer genetic testing	Genetic testing performed in a do-it-yourself manner -> direct connection between tested person and offering company	See description
20	Medical use of PGT	New PGTs, healthcare procedures, clinical eligibility criteria for PGT (i.e., eligibility for screening)	See description
21	Disclosure of disease risks	Doctor-patient relationship (counselling, information etc); right not to know; incidental findings; uncertainty	See description
22	Case story of affected person	Examples / cases / statements of people living with a genetic risk, their family → code case stories of celebrities in Public debates (15)	PGT in general
23	Preventive treatment	Only when in relation to a genetic risk -> preventive surgeries, preventive examination, preventive drugs	See description
14	Public health	implementation of genetic testing into healthcare (e.g. by NHS); general guidelines regarding PGT (i.e., screening, clinical use, preventive treatment, etc.), "genetic revolution", personalized medicine, genetics in society	See description
15	Public debates about PGT	Political discussions, public debates, going public (excl. Angelina Jolie), case story of a celebrity	See description
17	Legal and economic aspects	Actual law changes, patenting, public health economics, insurance coverage/prices of PGT	See description
16	Angelina Jolie case	Everything directly related to Angelina Jolie's statement, effects, etc.	See description
13	Research about predictive genetic testing	Any research study, new findings, research has shown -> including clinical trials! → regarding genetic data for research, please code 12	See description
18	Ethical issues	Discrimination, stigmatization, privacy, data protection, data sharing, confidentiality issues	See description
11	Information (facts) about predictive genetic testing	Background information about predictive genetic testing in general	PGT in general
12	Genetic data / WGS	Big Data / looking at the whole genome instead of certain genes (Whole Genome analysis) / data sharing platforms	See description
99	Other (please specify)		
999	Article not included – stop coding!		

Source/stakeholder list

0	No source attributed	Facts without explicit information about source
10	Media (rest)	<i>Please state in the comment section</i>
11	Journalist / person writing the article	Stating clear personal opinion; including letter to the editor
12	Other journalist	
14	News agency	e.g. SDA, DPA, PA, Reuters, AP: if news agency is stated in brackets below the article, its predominance is considered unclear (0)
15	Other medium	e.g. TV, article in the same newspaper or in a different newspaper is cited
20	Research/medicine (rest)	<i>Please state in the comment section</i> → Code general term "experts" here!
21	Natural / medical science	Person / research group / research organisation: Natural scientist, not treating patients directly but have a role as a researcher <i>Cave: could be an MD! But the way the person is presented in the text it's a research function and not a patient treating function</i>
22	Social science / art & humanities / law	Person, research group or research organisation - Bioethicist / philosopher / theologist ...
23	Medical doctor / geneticist / nurse	Person: <u>Treats patients</u> , working as an MD is specifically mentioned Organisation: hospital, medical institutes
24	Research study / article / journal	Source: i.e. a paper cited
25	University	Source: On an institutional level
30	Economics/company (rest)	<i>Please state in the comment section</i>
31	DTC company	Source or person – if products are sold to consumers directly
32	Pharma company	Source or person – if not a DTC company
33	Biotech company	Source or person – if not a DTC company
40	Society/individual (rest)	<i>Please state in the comment section</i>
41	Affected patient	Person with a positive genetic risk for a certain disease (e.g. cancer) --> <i>cave: can be healthy, but has an increased risk to get a serious illness!</i>
42	Healthy genetic test user	A healthy person using a predictive genetic test
43	Family of affected patient or healthy genetic test user	Family members of an affected person
44	VIP / celebrity	e.g. VIP/celebrity that makes genetic predisposition and/or preventive treatment public (Angelina Jolie, Kelly Osborne, Betty Ford etc.)
50	Public institutions / health (rest)	<i>Please state in the comment section</i>
51	Political system / politicians / political commission national	Statements from political system in general, parliament, politicians etc. (can be persons or organizations!), courts, Health Department
52	Political system / politicians / political commission international	Statements from political system in general, parliament, politicians etc. (can be persons or organizations!), courts, Health Department
53	Governmental organisation	Any institution financed by government , e.g. Swissmedic, SNF, FDA, NIH, NHS, National Institute for Health and Care Excellence (Nice), counseling inst. (i.e. Medical Research Council) → check online 53 vs. 55
54	Health insurance	Coverage of predictive genetic test / policies of health insurances; citation of a health insurance's statement
55	Non-governmental organizations	Not financed by or relying on government, e.g. Patient organizations / NGOs / charity / civil movement / professional bodies / foundations ...
90	Other	<i>Please state in the comment section</i>
91	Church / religious group	

