



**QIMR Berghofer**  
Medical Research Institute

# **Literacy challenges for science communication and complex trait genetics**

## **Insights from text mining and survey studies**

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# Background

Two major topics in public understanding of genetics:

- (i) the prevalence and consequences of *genetic determinism*.
- (ii) the portrayal of genetics in the news.



# Background

- Believing that human behaviour is *determined* by genes is erroneous and considered a crass exaggeration.
- It is associated with negative social consequences.
- Better genetic literacy would promote realistic interpretations of complex trait genetics.



# Background

- Online media has become the main source of scientific information for many individuals.
- Useful tool to promote genetic literacy.
- The enormous amount of online content that is generated nowadays makes its analysis a challenge.

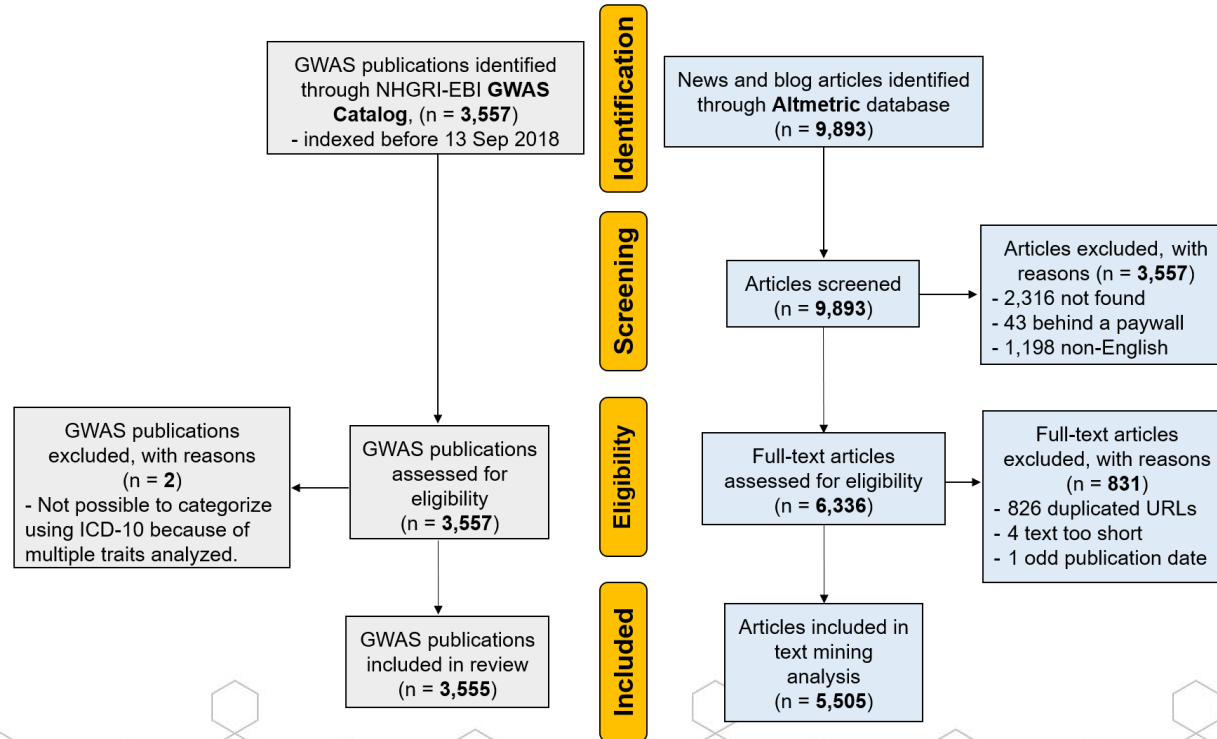


# Present study

1. First systematic text mining review of online media coverage of genome-wide association studies.
2. Subset of results about genetic literacy levels in general population from a survey on public interest in genetic testing for mental health disorders (N=4,975).



# Systematic review of news websites



# Workflow visually



 **HHS Public Access**  
Author manuscript  
*Nat Genet.* Author manuscript; available in PMC 2017 January 30.

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**Genome-wide analyses for personality traits identify 100 genomic loci and show correlations with psychiatric disorders**

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DAILY NEWS 25 June 2018, updated 27 June 2018

## There are two types of worrier – which you are depends on genes

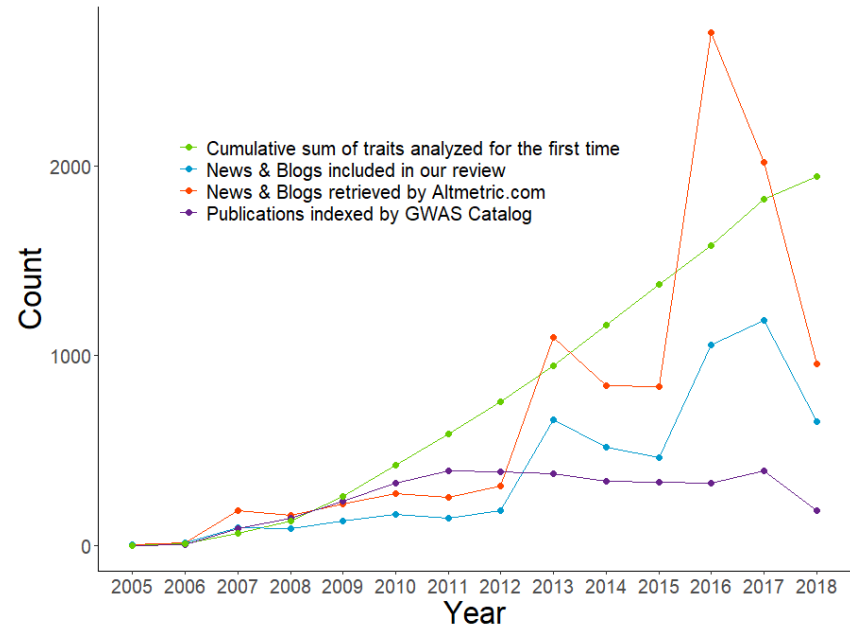


rank	headline	category	url	# of genes	rank	url	no. citations
5	01-07-11 14:30 Predicting megatrends in Genetics and bioinformatics medicine		In part of this series, I learned up Alan Guttmacher's 2006...	41,058	146	1	Science
9	12-12-17 23:13 Is your ADHD related to obesity risk?		Child obesity rates are skyrocketing globally. Young children...	30,028	982	0	Science
10	05-04-10 22:00 NSF - The Best Is Born In My Genes!		Michael and Elizabeth (Eli) Elgert make a selection...	30,028	982	0	Science
11	01-02-07 12:00 Genes and Cancer		Just how do the Weizmann Center researchers do it...	30,028	982	0	Science
14	01-02-07 0:58 Scientific discovery: science is hard		Ever since 1949, it has been a long-time consensus that S...	24,176	1001	1	Nature Genetics
15	15-11-05 0:45 Genomes and social health care		On this site, we offer info to public genetics resources like...	24,176	1001	1	Nature Genetics
16	10-05-08 0:32 DSM 5: what do I tell a kid?		How do I tell a gene a kid is on the spectrum for autism?	24,176	1001	1	Nature Genetics
18	02-06-07 12:53 The cost of memory?		Do our genes make a difference? Memory and mood. That's...	30,028	982	0	Science
19	17-10-06 10:21 A gene that affects memory		A landmark study, published in Science, indicates that a...	30,028	982	0	Science
21	20-10-06 0:43 Memory associated SNP		I'd pointed out this paper in the new issue of Science. The "...	30,028	982	0	Science
22	21-04-02 17:39 Genome Wide Association Values		There was an interesting post over at GenesFuture on why...	30,028	982	0	Science
23	03-10-08 12:00 Common disease, common variant		Current debate in common disease genetics got a bit...	30,028	982	0	Science
24	20-06-07 0:30 Being brave		The last 2 weeks have been somewhat busy in preparation fo...	3,300	675	0	Cancer Letters
25	06-08-17 16:10 Scientists are finding more genes linked to IQ. This doesn't		Researchers using huge data sets to understand genetics an...	28,751	1275	3	Nature
26	22-02-07 2:13 A Genome-wide Association Study to Find Genes Linked to		I want to get this post about an important new paper up. I...	28,751	1275	3	Nature
27	14-02-07 0:13 Mendelian Randomization		Excellent, unique thesis in terms of identifying phenotypic...	28,751	1275	3	Nature
16	12-09-07 16:14 All children of the line		Working with the diabetes theme, the first genome-wide an...	28,751	1275	3	Nature
17	17-02-07 0:30 Finding for the Missing Heritability of A1C		Scientists have not nearly plumbed the depths of genetic an...	10,169	547	0	Level HearingLab
18	17-04-06 0:43 Genes can push you toward obesity, but there are things yo		The role of genes in obesity is one of science's great puzzles...	28,751	1275	3	Nature
19	17-04-06 0:43 Why it's useful to understand the role of genetics in behav		Scientists have studied genes for many years to understand h...	28,751	1275	3	Nature
20	17-04-06 0:43 Finding Genetic Links on Obesity?		When weight loss is the goal, the question seems simple en...	28,751	1275	3	Nature
21	17-04-06 0:43 Mouse models that control fat cells may lead to obesity cure		A team of MIT and Harvard researchers found a genetic pat...	28,751	1275	3	Nature
22	17-04-06 0:43 Why Both Genes and Family Matter in the Obesity Epid		People with a specific mutation in one gene are substantially...	28,751	1275	3	Nature
23	17-04-06 0:43 Self-control for overeating: How genes affect your we		A new paper in PNAS reports on how the effect of a variant...	28,751	1275	3	Nature
24	17-04-06 0:43 A New Understanding of a DNA Repair/Genome Stability		As you know if you've been following this blog for a while, i...	28,751	1275	3	Nature
25	17-04-06 0:43 Obesity Researchers Have Been Looking At The Wrong Gene		If you're wondering investigating a certain gene, you wouldn't ju...	28,751	1275	3	Nature
26	17-04-06 0:43 Metabolism: Obesity's secret foe		The modelled "obesity score" of being born with a slow met...	28,751	1275	3	Nature
27	17-04-06 0:43 140 Rare Gene Linked: Mutations Found In Protein		Scientists say they've discovered the secret behind the link...	28,751	1275	3	Nature



# Results from text mining analysis

- More GWAS publications and associated media every year.
- Only 22.9% of published GWAS had coverage.
- 40% of news were identical or rephrased content from another website.
- 95% of news require a college graduate reading ability.





# Results from text mining analysis

Mentions of clinical implications in GWAS appeared more frequently from 2015 onwards.

- 'prevent' (24.8% of 5,505 news articles)
- 'therap\*' (23.7%)
- 'screening' (7.4%)
- 'precision medicine' (2.4%)
- 'detection' (2.3%)
- 'pharmacogenomics' (0.9%)

# Results from text mining analysis

However, appearance of terms associated with ethical and social issues remained low over the years

- 'policy' (2.7% of news articles)
- 'ethic\*' (2.1%)
- 'minorit\*' (1.9%)
- 'privacy' (1.4%)
- 'stigma' (1.2%)
- 'discrimination' (0.9%)
- 'insurance' (0.7%)
- 'eugenic\*' (0.9%)



# Survey study

- (i) Families that had already participated in genetic research studies at QIMR Berghofer, Australia (N=3,974)
  - (ii) general population from U.K. (N=501) and U.S. (N=500) via Prolific Academic.
- 
- **Genetic literacy was measured with 33 statements.**
    - True, false or “I don’t know” (i.e., “Most human traits and diseases are caused by a single gene”).
    - Modified REAL-G: How familiar are you with each one of these terms? Genetics, Chromosome, Susceptibility, Mutation, Genetic variant, Heredity, Polygenic.



# Survey study

## Sample size



N = 3,974



N = 501



N = 500

## Gender



64.6% women

62.9% women

47.6% women

## Age



17-86 y.o.

18-75 y.o.

18-76 y.o.

## Education

*University degree*



57.5% university

51.7% university

47.6% university

## Genetic literacy

*>75 correct answers*



13.7%

13.8%

14.6%



# Results from literacy survey

	<b>Australia (QIMRB)</b>	<b>United Kingdom</b>	<b>United States</b>
	N = 3,974	N = 501	N = 500
<b>How familiar are you with each one of these terms? (% familiar or completely familiar)</b>			
<i>Genetic variant</i>	44.9	35.3	45.7
<i>Polygenic</i>	20.2	14.6	21.3
<b>Most human traits and diseases are caused by a single gene (F)</b>			
Correct answer (%)	75.7	57.7	66.4
<b>A single gene can influence several different traits or diseases (T)</b>			
Correct answer (%)	95.1	72.8	81.7

# Results from literacy survey

**Australia (QIMRB)**

**United Kingdom**

**United States**

N = 3,974

N = 501

N = 500

**The kind of person someone is can be largely attributed to their genetic inheritance.**

Agree or strongly  
agree (%)

92.3

80.4

86.1

**There are different types of people and with enough scientific knowledge these  
different "types" can be traced back to genetic causes.**

Agree or strongly  
agree (%)

75.7

57.7

66.4

# Conclusions

- Genetic research is described in language too complex to be understood by the general public.
- Some key concepts (i.e., polygenic) are still not familiar for the majority of the public.
- There are extended beliefs about genetics shaping human behavior that could be harmful.



**Thank you**

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