

ONTARIO LIBRARY ASSOCIATION SUPER CONFERENCE 2016

Health Science, Public Trust and Celebrity Culture

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**Health
Literacy**

**Current
trends**

**Public
distrust**

**Health
literacy &
media**

**What is a
healthy
lifestyle?**

**Celebrity
medicine**

**Celebrity
worship**

**Celebrity
culture &
health**

**Social
impact**

**The
Angelina
Jolie
Effect**

**Media
coverage**

**Impact on
patients**

**Public
education**

**Libraries,
public
education
& dialogue**

**The role of
librarians**

What is health literacy?

- **Public Health Agency of Canada** defines health literacy as the ability to access, comprehend, evaluate and communicate information as a way to promote, maintain and improve health in a variety of settings across the life-course.
- Health literacy is ultimately about what constitutes a truly healthy lifestyle (e.g., diet, exercise, environment, etc.)
- Health advice on TV, the Internet, and social media is often complex. Health literacy levels in Canada are low.



Public distrust of science

PEW RESEARCH Centre Report on The Public and Scientists' views on Science and Society from January 29, 2015

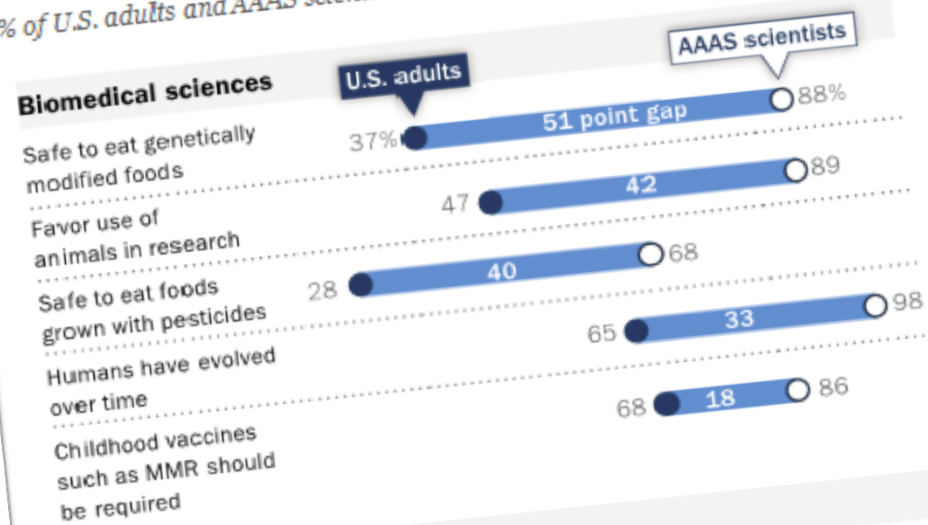
- 79% of the 2,000 adults surveyed think science has “made life easier for most people.”
- 71% think that investment in science ultimately pays
- **Yet, there is a sizable opinion gap between the general public and scientists on a broad range of science and technology topics, and biomedical science in particular**

<http://www.pewinternet.org/2015/01/29/public-and-scientists-views-on-science-and-society/>

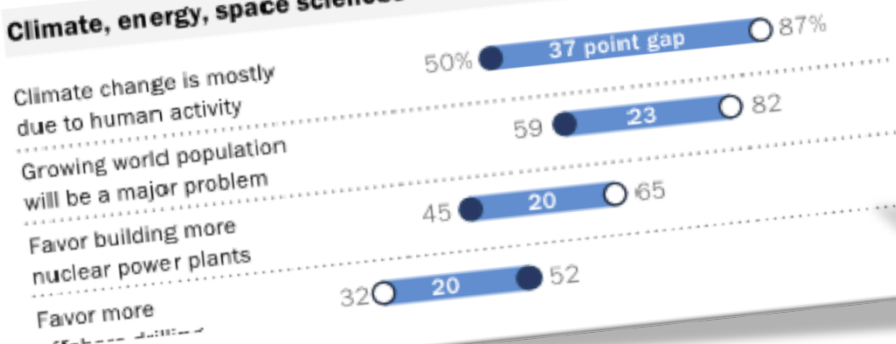
Opinion gap attributed to the lack of scientific literacy

Opinion Differences Between Public and Scientists

% of U.S. adults and AAAS scientists saying each of the following

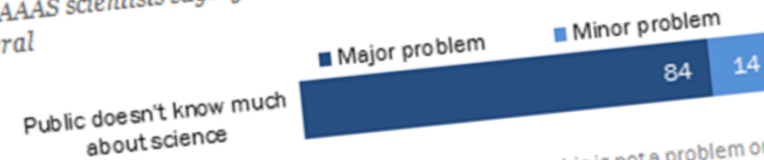


Climate, energy, space sciences



Scientists' Perspective: Limited Public Knowledge About Science Is a Major Problem

% of AAAS scientists saying... is a major or minor problem for science in general

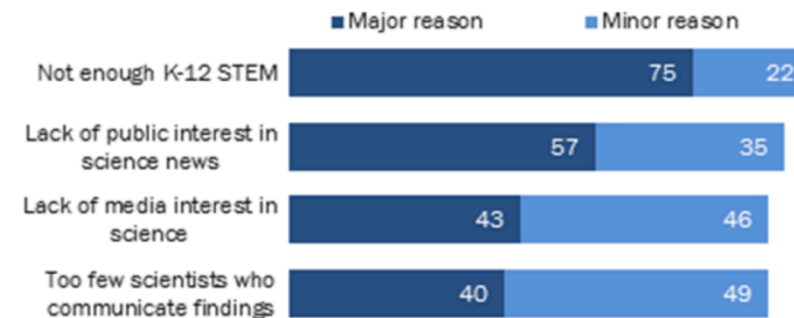


AAAS scientists survey Sept 11-Oct 13, 2014. Q5d. Those saying this is not a problem or giving no answer are not shown.

PEW RESEARCH CENTER

Scientists' Perspective: Too Little K-12 STEM Linked to Limited Public Science Knowledge

% of AAAS scientists saying each is a major/minor reason for the U.S. public having limited knowledge about science



AAAS scientists survey Sept 11-Oct 13, 2014. Q6a-d. Those saying not a reason or giving no answer are not shown.

PEW RESEARCH CENTER

Celebrity medicine

HOME DIAGNOSIS CELEBRITIES #CELEBRITYDX CHAT

7 Gwyneth Paltrow felt the heat

Celebrity Diagnosis Monthly Twitter Chat

7 SHARES

f SHARE

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p SHARE

g+ SHARE

0 COMMENTS

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What: Join the live conversation with [Dr. Michele Berman](#) discussing health issues, celebrity disease, and how Teachable Moments in Medicine are paving the way for public education.



Where: Twitter! If you don't have an account, simply visit [Twitter.com](#) and create one.

When: April 24th from 8-8:30pm EST

How: To participate, follow these simple instructions!

Create or login to Twitter; Type in the hashtag #CelebrityDx into the search bar to find all tweets related to the chat; Tweet your questions directly to [@CelebrityDx](#) and learn more about health trends, diets, fads, and anything else you may have questions about!

*This is not designed to treat personal health ailments, but rather an educational forum and dialogue.

POPULAR

LATEST

COMMENTS



Kelly Ripa Diagnoses Herself With Mysterious Neurological Disorder



"Cake Boss" Mama Mary Valastro Diagnosed With ALS



Angelina Jolie Feeds Her Kids Bugs!



Did "Alternative Medicine" Kill Steve Jobs?



Tisha Campbell-Martin reveals she has Sarcoidosis.

Celebrity medicine is a
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Celebrities have impact on individual health-related decisions



- An Australian study found that celebrities appear central to TV news coverage of specific cancers, especially breast cancer
- Nancy Reagan's breast cancer in late 1987 led to a decrease in breast-conserving surgery in her demographic group (50–79 years) and among women with lower income and educational status
- Kylie Minogue's breast cancer diagnosis in 2005 resulted in an unprecedented increase in screening by mammography in Australia (e.g., *bookings for mammograms rose by 40% in four Australian states*)

Angelina Jolie's op-ed in NY Times

OP-ED CONTRIBUTOR

My Medical Choice

By ANGELINA JOLIE

Published: May 14, 2013 |  1712 Comments

LOS ANGELES

 [Enlarge This Image](#)



MY MOTHER fought cancer for almost a decade and died at 56. She held out long enough to meet the first of her grandchildren and to hold them in her arms. But my other children will never have the chance to know her and experience how loving and gracious she was.

We often speak of “Mommy’s mommy,” and I find myself trying to explain the illness that took her away from us. They have asked if the same could happen to me. I have always told

I have a “faulty” gene, BRCA1, which sharply increases my risk of developing breast cancer and ovarian cancer. My doctors estimated that I had an 87 percent risk of breast cancer and a 50 percent risk of ovarian cancer, although the risk is different in the case of each woman. **Only a fraction of breast cancers result from an inherited gene mutation.** Those with a defect in BRCA1 have a 65 percent risk of getting it, on average.

Jolie's preventive mastectomy: Did media get it right?

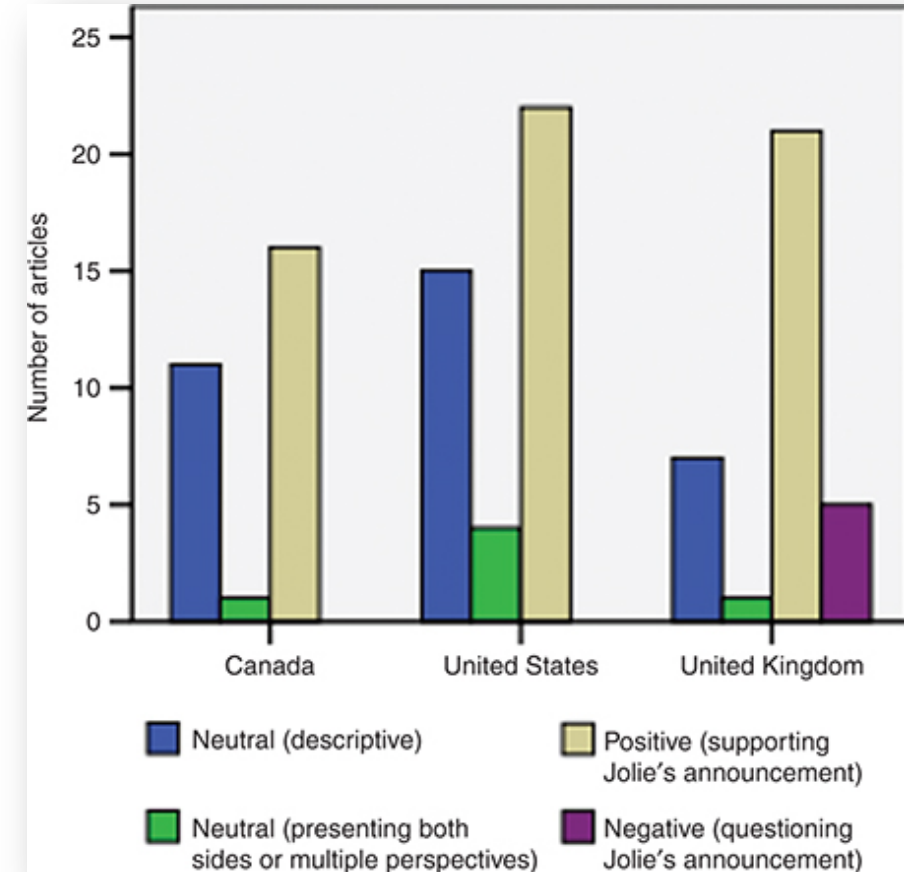
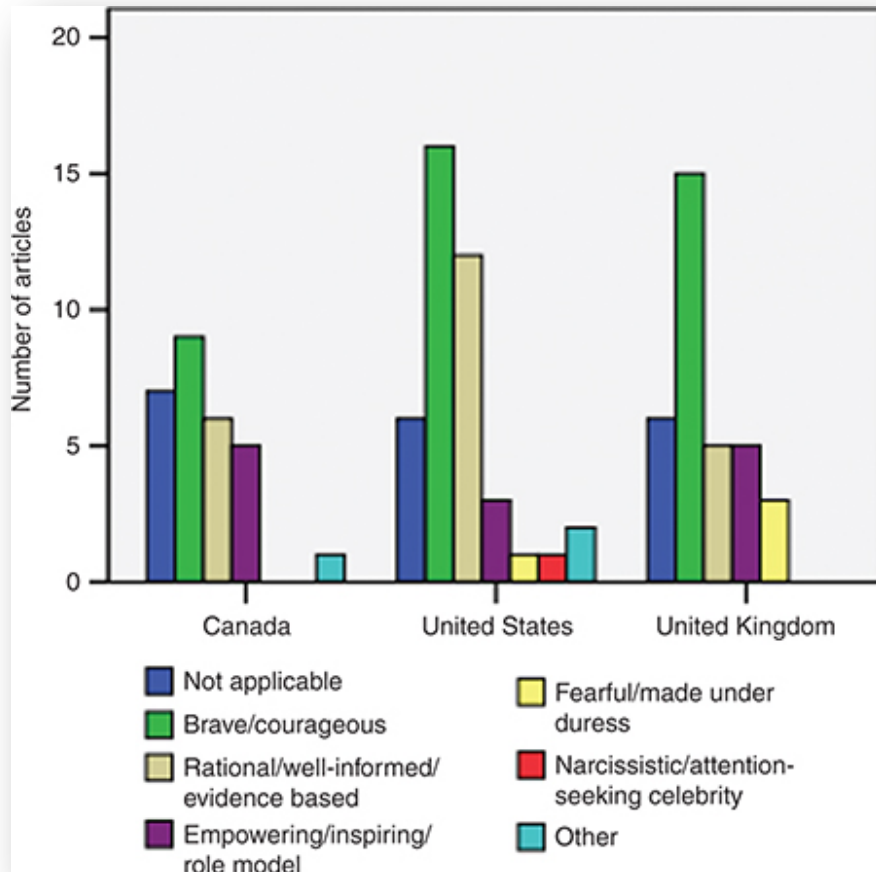
Newspaper	Country	No. of articles	Articles in data set (%)
<i>The Globe and Mail</i>	Canada	9	8.7
<i>The Montreal Gazette</i>	Canada	3	2.9
<i>National Post</i>	Canada	5	4.9
<i>Toronto Star</i>	Canada	9	8.7
<i>Vancouver Sun</i>	Canada	2	1.9
<i>The Los Angeles Times</i>	United States	4	3.9
<i>The New York Times</i>	United States	18	17.5
<i>USA Today</i>	United States	10	9.7
<i>The Wall Street Journal</i>	United States	4	3.9
<i>The Washington Post</i>	United States	5	4.9
<i>The Daily Telegraph</i>	United Kingdom	10	9.7
<i>Financial Times</i>	United Kingdom	3	2.9
<i>The Guardian</i>	United Kingdom	5	4.9
<i>The Independent</i>	United Kingdom	3	2.9
<i>The Times (London)</i>	United Kingdom	13	12.6
Total		103	100

- Content analysis of press coverage in elite/high quality newspapers in Canada, US, and the UK, May 13 - June 12, 2013
 - 1) Large, broadsheet format
 - 2) More text overall and longer, more serious articles
 - 3) Focus on **“hard news”** (i.e., economics, national and international politics)
 - 4) Content intended for a more educated, middle to high class audience
 - 5) Higher quality of journalism and standards of ethical practice

How was Jolie's mastectomy portrayed?

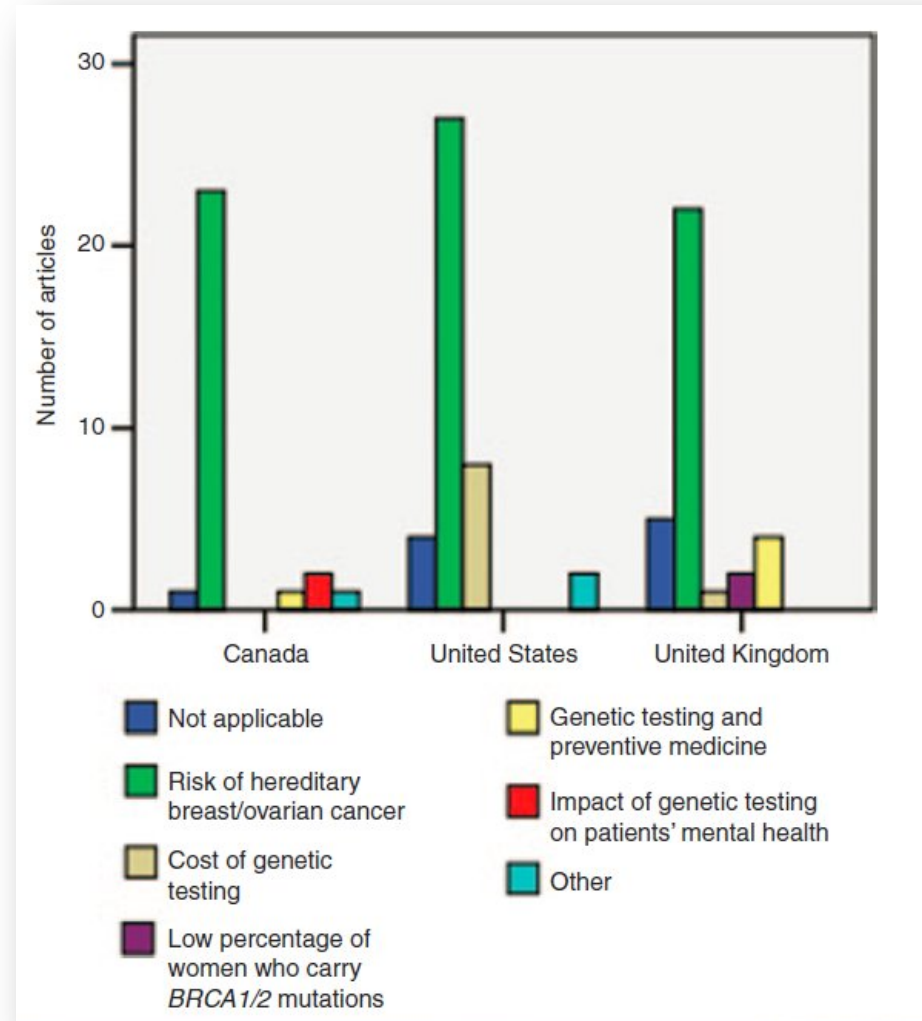
Media framed Jolie's medical choice primarily as brave and courageous – 38.8% of the articles

An overall positive slant towards Jolie's mastectomy – 57.3% of the articles



Important issues concerning predictive genetic testing were considered

- 69.9% highlighted the increased risk of hereditary breast/ovarian cancer for carriers of BRCA1/2 gene mutations
- The gene patenting controversy was the primary focus in 10.7 % of the news stories



Issues that were overlooked in the newspaper stories

- Only 18% of articles mentioned the possible drawbacks of preventive mastectomy
- Only 11% of articles cautioned that Angelina Jolie's story could influence women to choose preventive surgery without having an assessment of their genetic risks
- **Most importantly, 68% did not mention the rarity of Jolie's condition** (e.g., that harmful BRCA1/2 mutations are relatively rare in the general population and account for only 5–10% of all breast cancers)
- **Overall media failed to emphasize the need for evidence-based assessment of breast cancer risk and preventive options**

Media hype surrounding Jolie's mastectomy

- Jolie seems to have had a larger impact compared to other celebrities
- She projects the image of a glamorous and strong woman and this may have lessened patients' fears about a loss of sexual identity as a result of preventative surgery
- Her educational op-ed may have encouraged those who had not previously engaged with health services to consider genetic testing



The Angelina Jolie story did NOT increase the public understanding of breast cancer risks associated with BRCA1/2 mutations

© American College of Medical Genetics and Genomics

ORIGINAL RESEARCH ARTICLE

Genetics
in Medicine

The Angelina effect: immediate reach, grasp, and impact of going public

Dina L. G. Berzuckewski, EdD¹, Yue Guan, ScM², Katherine C. Smith, PhD², Lori H. Erby, PhD² and

Less than 1 in 10 adults gave accurate answers about BRCA1 mutations and breast cancer risk

Background: In May 2013, Angelina Jolie revealed in a *New York Times* opinion piece that she had undergone a preventive double mastectomy, a rare personal health story. While the story was widely disseminated, but it is not obvious what messages the public took from this personal health story.

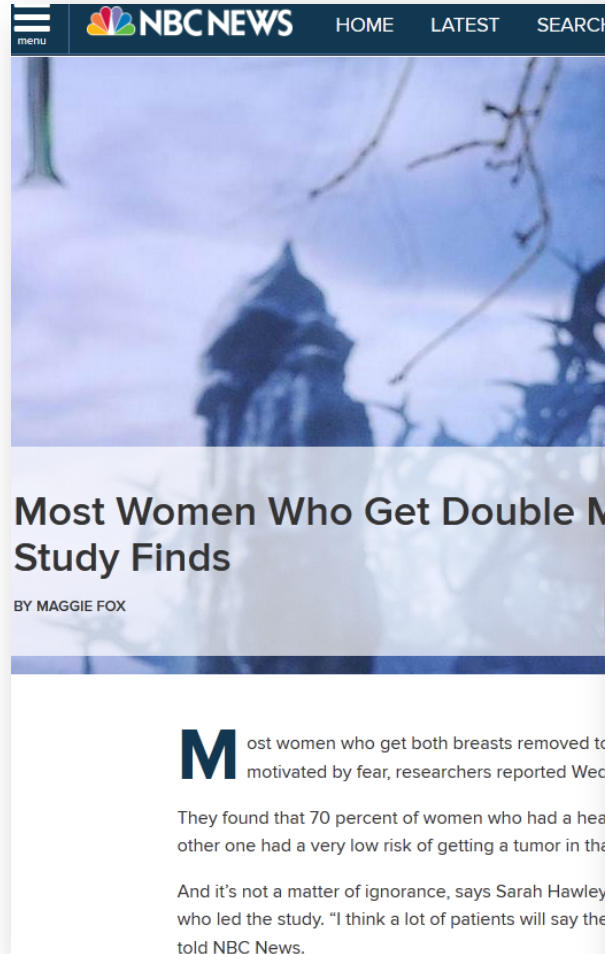
Methods: We conducted a survey with a representative national online panel of 2,572 adults. Participants described their awareness and identified information sources for the Angelina Jolie news story. They also

Results: While three of four Americans were aware of Angelina Jolie's double mastectomy, fewer than 10% of respondents had the correct answer to a question about BRCA1 mutations. Awareness of the Angelina Jolie story was not associated with improved understanding.

Conclusion: While celebrities can bring heightened awareness to health issues, there is a need for these messages to be accompanied by more purposeful communication efforts to assist the public in under-

Women's perceptions were less accurate than men's

Impact on patients' choices of treatment option



70% of Mastectomies Aren't Necessary. Here's Why Women Have Them Anyway

Alice In fact, only 10% of women diagnosed with breast cancer should consider such prophylactic mastectomy

Sci treatment doesn't lower risk her pro clin

"There is a hyper awareness surrounding prophylactic mastectomy, and many women are choosing it without a clear understanding of why"

In a new study published in *JAMA Surgery*, researchers say that 70% of women with breast cancer in one breast who decide to

Increased referrals for genetic counselling and testing

Evans et al. *Breast Cancer Research* 2014, **16**:442
<http://breast-cancer-research.com/content/16/5/442>



RESEARCH ARTICLE

Open Access

The Angelina Jolie effect: how high celebrity profile can have a major impact on provision of cancer related services

D Gareth R Evans^{1,2,14†}, Julian Barwell^{3†}, Diana M Eccles⁴, Amanda Collins⁴, Louise Izatt⁵, Chris Jacobs⁵, Alan Donaldson⁶, Angela F Brady⁷, Andrew Cuthbert⁸, Rachel Harrison⁹, Sue Thomas¹⁰, Anthony Howell¹, The FH02 Study Group, RGC teams, Zosia Miedzybrodzka^{11,12} and Alex Murray¹³

Abstract

Introduction: It is frequent for news items to lead to a short lived temporary increase in interest in a particular health related service, however it is rare for this to have a long lasting effect. In 2013, in the UK in particular, there has been unprecedented publicity in hereditary breast cancer, with Angelina Jolie's decision to have genetic testing for the *BRCA1* gene and subsequently undergo risk reducing mastectomy (RRM), and a pre-release of the NICE guidelines on familial breast cancer in January and their final release on 26th June. The release of NICE guidelines created a lot of publicity over the potential for use of chemoprevention using tamoxifen or raloxifene. However, the longest lasting news story was the release of details of film actress Angelina Jolie's genetic test and surgery.

Methods: To assess the potential effects of the 'Angelina Jolie' effect, referral data specific to breast cancer family history was obtained from around the UK for the years 2012 and 2013. A consortium of over 30 breast cancer family history clinics that have contributed to two research studies on early breast surveillance were asked to participate as well as 10 genetics centres. Monthly referrals to each service were collated and increases from 2012 to 2013 assessed.

Results: Data from 12 family history clinics and 9 regional genetics services showed a rise in referrals from May 2013 onwards. Referrals were nearly 2.5 fold in June and July 2013 from 1,981 (2012) to 4,847 (2013) and remained at around two-fold to October 2013. Demand for *BRCA1/2* testing almost doubled and there were also many more enquiries for risk reducing mastectomy. Internal review shows that there was no increase in inappropriate referrals.

Conclusions: The Angelina Jolie effect has been long lasting and global, and appears to have increased referrals to centres appropriately.

- Impact has been “long-lasting and global.” In fact, Referrals for genetic counseling in the UK increased by 2.5 times
- Referrals for genetic testing also increased, with seven Regional Genetics Centers seeing an 80% increase in full *BRCA1/2* between July 2013 and December 2013 compared to the year prior

What could librarians do to counter the negative influence of celebrity medicine?

- Encourage people to read more about healthy lifestyles and health services
- Speak about the validity of the celebrities' advice
- Recommend sources of reputable health information, especially when people seek information about the latest celebrity endorsement



Acknowledgements

My co-authors Timothy Caulfield & Amir Reshef and former colleagues at the University of Alberta's Health Law Institute, including Robyn Hyde-Lay, Ubaka Ogbogu, Christen Rachul, Zubin Master, Amy Zarzeczny, Sarah Burningham, Maeghan Toews, Marianne Clark, Brice Goldfeldt, and Adam Ollenberger

The study on Angelina Jolie and celebrity medicine was conducted under the PACEOMICS Project (Personalized, Accessible, Cost-Effective Applications of 'Omics Technologies), funded by Genome Canada/Genome Alberta, CIHR, and Alberta Health & Wellness.

PACEOMICS

Thank you!

Questions/comments?