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## Section 5: Research Trends

The peculiar persistence of medical myths: how to counter and discourage misinformation

Mike Taylor

Medical misinformation is unusually persistent in society. Despite the withdrawal of the paper that provoked the measles-mumps-rubella vaccine scandal, countless studies rebutting the findings, and the professional disgracing of the principal author, the level of vaccination has not yet returned to pre-publication levels. Scientific and pseudo-scientific communication carries with it a certain weight of authority and responsibility. As access to research grows, and with it the potential for wide-spread social reach, the scholarly community needs to maintain and develop the caliber of its publishing, and develop more robust and authoritative methods of countering misinformation and overturned findings.

The industry surrounding the communication of medical facts to the lay community is substantial: there are dozens of magazines and 100,000s of websites devoted to communicating health facts ([https://www.google.com/?gws\\_rd=cr#bav=on.2.or.r\\_cp.r\\_qf.&cad=b&fp=1&q=%E2%80%9CHealth+facts%E2%80%9D](https://www.google.com/?gws_rd=cr#bav=on.2.or.r_cp.r_qf.&cad=b&fp=1&q=%E2%80%9CHealth+facts%E2%80%9D)) and once accepted into society, medical facts appear to have a particular resilience, whether based on medical research in good standing or

not. Snopes.com – a database of urban legends, rumors and myths – lists many such medical stories and their top 25 consists of approximately one-quarter health facts. Scientific research is also poorly served by the popular media. Vinegar: Secret to Fast Weight Loss (1), for example, contains approximately 21 claims regarding the weight loss and health-promoting properties of vinegar, of which only six have a partial reference to the literature – typically providing a journal title and year of publication only. Furthermore, one of the key references is a review, rather than research (2), which references a 2005 study (3) that may be considered flawed, as it has (partially) relied upon a subjective scale, appears not to have been conducted double-blind, and has a sample size of 12.

In this article, I investigate the publishing history of three medical memes and detail their current status in literature and society. In addition, I use my findings to suggest methods that the scientific community could use to improve the quality and robustness of medical research publishing, in particular when the social impact is likely to be high. My investigation is supported by an informal and anonymous survey of 80 associates, most of whom work in science or an allied industry (see box below).

### Survey on medical knowledge

Respondents were asked to indicate their agreement with six medical sentences (see Table 1, p.22). They were able to respond using one of four statements: "I agree with the sentence", "I disagree with the sentence", "I used to agree with the sentence, but have changed my mind", "I used to disagree with the sentence, but have changed my mind". Respondents who had changed their mind were invited to give some reasons. Three of the sentences ("Spinach contains loads of iron and is particularly good for you", "Some people are made ill by Wi-Fi and mobile phone radiation" and "Some routine childhood vaccinations are sufficiently risky to make me not want to give them to my children") had been previously selected to feature in this article and are known to be untrue statements. The other three were chosen to provide some comparative figures and are mostly true. "A diet containing a lot of fat is unlikely to be very healthy" (aside from some particular biological requirements) may reasonably be observed to be true. "Male circumcision is unnecessary" described an emergent issue with some research in its favor, but has considerable religious importance (although there are medical conditions that can be ameliorated by circumcision), and that "cancer can be caused by a virus" is demonstrably true for at least two viruses (cervical cancer is caused by HPV and the wild Tasmanian Devil population is widely affected by a virus that causes cancer) - but is probably not common knowledge. The language was deliberately non-clinical, which caused comment amongst some respondents, but was aimed at encouraging a populist mode of response – i.e., respondents would hopefully respond instinctively, rather than engage in a literature search. Therefore, the survey was cued as taking "two minutes".

Free text responses were classified into three classes: those that provided no evidence, those that mentioned some formal evidence (research, professional opinion, citable evidence, review of research, etc.) and those that referred to non-formal evidence (generic reading, friends, mass media, etc.). Of the four statements, 'spinach', 'vaccine', 'fat' and 'Wi-Fi' had a majority of informal citations, and 'circumcision' and 'cancer-virus' had a majority of formal evidence (see Table 2, p.22).

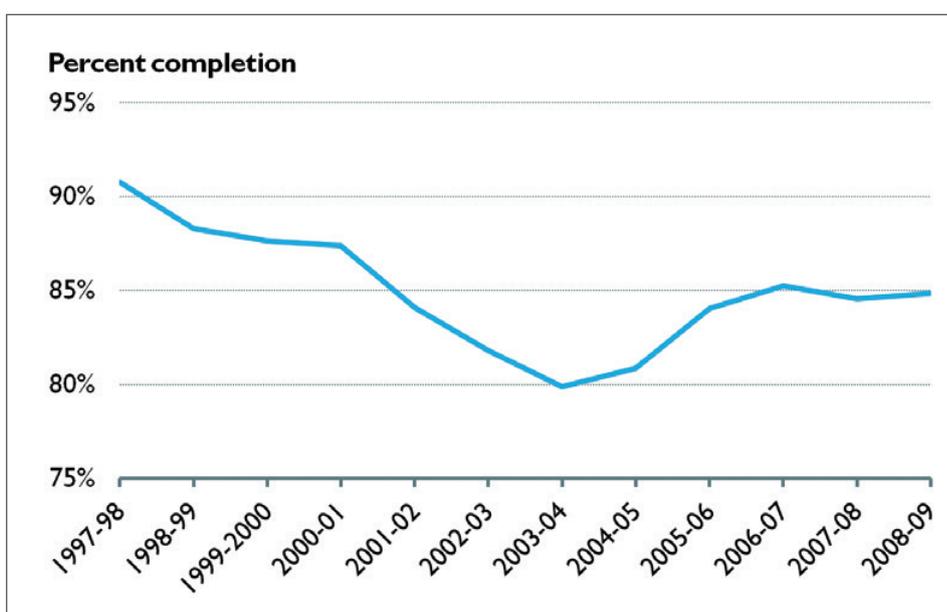
### Three medical memes without foundation that persist in popular belief

#### Failure to provide citations: the case of Popeye and spinach

The idea that spinach contains a disproportionate quantity of iron is a long-standing – but entirely false – belief. In fact, the true proportion of iron in spinach was well understood in the nineteenth century. That people have believed that spinach is peculiarly rich in iron has, for the last forty years, been attributed to two factors: (a) that the cartoon, Popeye, made that claim, as an explanation for Popeye's considerable consumption, and (b) that there had been, at some stage, a typographical error (misplaced decimal point) in an influential German publication of the early twentieth century. Extensive research by Dr Mike Sutton (4, 5) disproved both theories. Dr Sutton conducted an exhaustive review of the 'Popeye and spinach' literature, concluding that – as accurate figures were known at the beginning of serious food science – the error is the consequence of credulous re-reporting, lack of citation and lack of fact-checking, and potentially a swiftly corrected error in a US textbook of the 1930s. In particular, he cites the failure of Professor Hamblin (1981) to have undertaken any research in order to provide a citation for the decimal-point error in his *BMJ* article, 'Fake', and prior to that, Professor Bender (1977) who made the claim both in a speech and in a letter to the *Spectator* magazine; again without providing a resolvable citation. In correspondence with Dr Sutton, Professor Hamblin is reported to have said that he "may have read it in an unknown copy of the *Reader's Digest*". Despite this, 68% of my survey's respondents continue to agree with the sentence "Spinach contains loads of iron and is particularly good for you". 29 per cent of respondents who add an explanation cite the Popeye / decimal point error explanation for their belief. Furthermore, Dr Sutton's extensive literature review concluded that Popeye's dietary preference was because "Spinach is full of Vitamin 'A' an' tha's what makes hoomans strong an' hefty" (Segar, 1932, in Popeye, sic, all errors) (4, page 13).

#### Lack of evidence leads to a research dead-end: Electromagnetic hypersensitivity (EHS)

The idea that some individuals have a particular hypersensitivity to wireless or mobile electromagnetic radiation is a necessarily recent idea. Clearly the reported symptoms are distressing, and a sizeable number of preventative and diagnostic services and products are available for purchase (<http://www.emfields.org/shielding/overview.asp>).



**Figure 1:** Completed primary courses: percentage of UK children immunized by their second birthday, 1997-98 to 2008-09. Source: NHS Health and Social Care Centre (<http://www.hscic.gov.uk/catalogue/PUB00220>)

Successive studies, meta-studies and reviews (e.g. 6) have found that people who self-report electromagnetic-hypersensitivity are unable to detect electromagnetic radiation in double-blind conditions, although researchers note that these individuals appear to score higher for physiological discomfort in any condition (7). The continuous failure to find any evidence for electromagnetic hypersensitivity has resulted in a low volume of papers published in *Scopus*, with little or no growth (the last five years have produced an average of 11 papers per year). The World Health Organization concluded that it is not a diagnosable condition (8).

Despite this, 17.5% of people surveyed in the UK in 2007 reported their belief that they are – to some extent – sensitive to electromagnetic radiation (9). Although the majority (approximately 2:1) of people in this survey disagreed with the statement: "Some people are made ill by Wi-Fi and mobile phone radiation", a sizable proportion (31.4%) agreed with it. All comments that referred to an information source cited non-professional channels.

Despite the profound health implications for society, technology and the health of humanity if such a large proportion of people are sensitive to EMR, and the wide-spread belief in the syndrome, it appears that few people take any action, for example, by not using Wi-Fi, buying EMR shields or seeking "quiet zones".

In the case of electromagnetic hypersensitivity, it appears that a widely held belief has emerged despite the lack of any supporting evidence. Without any medical or economic motivations, it seems likely that research in this field – which consistently has failed to produce any positive biomedical results in support of an effect – will continue to drop-off, allowing the belief to persist.

#### Fraud and malpractice: Vaccination and MMR

In 1998, former doctor Andrew Wakefield (and others) published a fraudulent paper in the *Lancet* providing now discredited evidence linking the MMR vaccine to autism and bowel disease. Despite the action taken – (a) the withdrawal of the original paper, (b) subsequent studies and meta-studies that have failed to replicate the original paper's findings or find any other relationship, (c) Wakefield being struck off the Medical Register, (d) the many investigations that have found ethical and methodological mis-practice and finally (e) evidence that Wakefield had undisclosed financial interest in MMR being discredited, vaccination rates in the UK have not risen to their former, pre-*Lancet* publication highs (see Figure 1). As a consequence of low vaccination rates, there was a measles epidemic in parts of the UK in 2013 that resulted in at least one fatality. The UK health service ran a very high profile campaign, operating vaccination clinics in schools and work-places, keeping the story in the headlines during the course of the epidemic in order to reach an effective percentage of vaccination.

Despite the overwhelming evidence, some media outlets in the UK continue to publish stories referring to MMR as a 'controversial' vaccination (see box below). Although only two respondents to my survey expressed a belief that some vaccinations are significantly risky, clearly a considerable distrust continues to exist amongst British parents, as evidenced by the failure of the MMR vaccination rate to recover after the Wakefield scandal.

**The "controversial vaccine": MMR stories in the Daily Mail since 2009**

- MMR: A mother's victory. The vast majority of doctors say there is no link between the triple jab and autism, but could an Italian court case reignite this controversial debate? (2012) <http://www.dailymail.co.uk/news/article-2160054/MMR-A-mothers-victory-The-vastmajority-doctors-say-link-triple-jab-autism-Italian-court-case-reignite-controversial-debate.html>
- Six months after the MMR jab... a bubbly little girl now struggles to speak, walk and feed herself (2009) <http://www.dailymail.co.uk/health/article-1126035/Six-months-MMR-jab--bubbly-little-girl-struggles-speak-walk-feed-herself.html>
- American parents awarded £600,000 in compensation after their son developed autism as a result of MMR vaccine (2013) <http://www.dailymail.co.uk/news/article-2262534/American-parents-awarded-600-000-compensation-son-developed-autism-result-MMR-vaccine.html>

The recent epidemic of measles has resulted in sufficient publicity to change opinion about the relative risks, and the NHS has launched a campaign to vaccinate 1,000,000 children, in order to return to the pre-Wakefield levels of immunization (<http://www.nhs.uk/news/2013/04April/Pages/New-MMR-catch-up-campaign-one-million-children-targeted.aspx>).

**Changing minds: why misinformation is so persistent**

These medical myths – and many others – have much in common with urban myths:

"A story, generally untrue but sometimes one that is merely exaggerated or sensationalized, that gains the status of folklore by continual retelling (10)."

However, these medical myths have a peculiar characteristic: not only are they demonstrably untrue, but they appear

to defy logic by persisting in society, long after the evidence of their falsehood has been available.

Lewandowsky et al (11) explore a number of dimensions that may be applied to understand the persistence of misinformation: internal coherence, personal experience or knowledge, credibility and how widespread a belief is. In the case where medical doctors or scientists make an assertion, the source will be assumed to be credible, whereas the nature of the fact is likely to place it in the realm of the expertise: so a lay-consumer will lack the necessary experience or knowledge to rebut or refute a new claim. Furthermore, Heath et al. (12) observed that the greater the level of disgust associated with an urban legend, the more likely they were to be disseminated. (This intriguing observation allows us to conclude that if it had been strawberries, not spinach, which had been misidentified with superior iron, the myth would not have lasted so long, nor would have had the same impact.) This observation tallies with Berger's 2011 findings, that arousal increases social transmission of information (13).

Constructing a rebuttal that has a high probability of acceptance is complex. Lewandowsky et al. (14) demonstrated the importance of the perceived scientific consensus, researching the relationship between that perception and non-expert acceptance of those theories. Furthermore, he demonstrates that providing information about the consensus ("nine out of ten cats agree", "95% of dentists use") increases acceptance and that without this information, people frequently underestimate the meaning of consensus. Additionally, he reports studies that show that people accept consensus from trusted information sources (scientists), but not from authority figures.

Ecker et al. (15) demonstrated that belief will persist and that its level of influence will continue to increase in the absence of strong rebuttal, and that rebuttals require full attention in order to have maximal effect. Lewandowsky et al. (11) report that over-complexity of rebuttal and dogmatic assertions of correctness may reduce acceptance of the corrected information, and stress the need to offer a replacement narrative.

Thus, if we were to construct a rebuttal to the MMR vaccination issue, it might be characterized thus:

- The message would come from a trusted figure, rather than an authority.

- It would reference the degree of consensus ("97% of doctors...").
- The story would be simple.
- It would construct a replacement narrative, referencing personal experience and a new narrative ("Just as vaccines for polio, typhoid and diphtheria have kept generations safe...").
- There might be attempt to elicit arousal ("Wakefield was personally paid £435,000 to conduct research on children, including unnecessary and invasive procedures") - <http://www.bmj.com/content/342/bmj.c7001#ref-16>
- And rather than adding complexity to the message, further information should be made available to anyone who is interested.

If this sounds like advertising, we should reflect on the amount of investment and research undertaken by both industrial organizations and academics on the best strategies to change people's minds. In the case of this toothpaste advert, the authority figure is a "representation of a nurse": (<http://www.youtube.com/watch?v=pVFOorc-umM>), and these highly effective informational adverts (<http://news.bbc.co.uk/1/hi/health/8346497.stm>) that were designed to decrease the time taken for middle-aged stroke victims to seek medical attention were voiced over by an actress famous for playing a doctor in a UK TV series (<http://www.youtube.com/watch?v=1VhCYp6Ad4>). Both examples are constructed with a view to changing or replacing a narrative, whether it is that Toothpaste A is better than Toothpaste B, or that strokes affect older people or involve dramatic symptoms. The adverts construct narratives ("When stroke strikes, act FAST"), using a judicious mix of authority and evidence, but at all times maintaining a clear message.

**Trustworthy communication**

Despite the bizarre omission of a category for 'scientist, researcher or academic', professions with a scientific background are highly trusted, with five (nurses, pharmacists, medical doctors, engineers and dentists) appearing at the top of Gallup's Honest/Ethics in Professions ranking (<http://www.gallup.com/poll/1654/Honesty-Ethics-Professions.aspx#5>). Furthermore, scientific publishing is seen as of a different caliber from other forms of publishing, with the peer-review process often being used as a hallmark of quality. Entwistle reported that "Journalists relied heavily on the peer review processes of the journals in ensuring accuracy." (16)

Within the scholarly community, however, we have a more sophisticated view of the meaning of peer-review, and are able to take into account other phenomena. In short, we are able to take into account other pieces of information: for example, low citation rates and lower quality impact factors, the construction of the title and abstract, the reputation of the authors within their community - without necessarily engaging our subject-level expertise in an in-depth analysis of the methodology, analysis and conclusions. The process of peer-review is not a "gold standard" with a fixed methodological process, rather is it a term that encompasses many different forms of practice. Journals are re-visiting the process (e.g. *Virology*, <http://elsevierconnect.com/new-streamline-peer-review-process-piloted-by-virology/>), start-ups are proposing peer-review as a commercial service (<http://www.rubriq.com/>) and new publishers are experimenting with an open, non-anonymous peer review (<http://www.f1000.com>).

As scholarly communication becomes more freely available with the growth of open access – and we become more aware of concepts like "citizen science" ([http://en.wikipedia.org/wiki/Citizen\\_science](http://en.wikipedia.org/wiki/Citizen_science)) – it is worth considering how scholarly articles can be consumed in the wider community, especially when research is calculated to have the potential for being highly impactful:

a paper on the dangers of childhood vaccination will always have more potential than articles on bibliometrics, especially when surrounded with the paraphernalia of press releases, press conferences and media appearances that are calculated to provide added impetus to a story.

There are many emergent approaches to how we can position research in society, retaining the channel for the researchers, publishers and readership to communicate together, and how we can provide more information regarding the likely reliability of research outcomes.

- Crossref's Crossmark service (<http://www.crossref.org/crossmark/index.html>) provides a mechanism by which publishers can communicate errata, corrections in a standardized format.
- The Reproducibility Initiative – an initiative supported by Mendeley – aims to increase the rigor of scientific work, by reproducing experimental work using a blind, independent team (<https://www.scienceexchange.com/reproducibility>).
- The Amsterdam Manifesto on Data Citation (<http://www.force11.org/AmsterdamManifesto>) proposes a set of best practices to ensure that data is openly available, and that researchers can get credit for making their data available for error checking, re-use and re-analysis.

The problems surrounding withdrawn articles are likely to increase. The authors of the blog "Retraction Watch" (<http://retractionwatch.wordpress.com>) have published a detailed article on the phenomena of increasing retractions. "Why Has the Number of Scientific Retractions Increased?" (17) indicates a variety of causes: editors act faster, and more frequently. Retraction of one paper will lead to a re-evaluation of a researcher's other papers, and greater scrutiny of higher-impact journals has a 'modest' impact on retraction.

Increasing openness is likely to increase the rate of retraction, correction and erratum. Given how hard (and expensive) it is to retract misinformation, it seems reasonable to conclude that:

1. papers with a higher degree of likely social interest and impact should merit a higher standard of review, and that those standards should be open and readily understood by all readers, and
2. that when high-impact papers are retracted, retraction is insufficient, and that the "withdrawal" of the findings from the social melee should recognize the long-standing nature of scientific belief, and the likely cost to society of misheld beliefs.

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Appendix:

	I agree with the sentence	I disagree with the sentence	I used to agree with the sentence, but have changed my mind	I used to disagree with the sentence, but have changed my mind	Notes
Spinach contains loads of iron and is particularly good for you	68.4% (54)	2.5% (2)	26.6% (21)	2.5% (2)	See this article for more information; however spinach does not contain more iron than other green vegetables.
A diet containing a lot of fat is unlikely to be very healthy	62.5% (50)	12.5% (10)	21.3% (17)	3.8% (3)	Aside from the biological need for some lipids, this may be reasonably said to be true.
Some routine childhood vaccinations are sufficiently risky to make me not want to give them to my children	2.5% (2)	88.8% (71)	6.3% (5)	2.5% (2)	See this article for more information. Although there are various rumors regarding vaccination (“immune system overload” and “mercury” amongst them), this article focuses on the UK MMR scandal.
Some people are made ill from Wi-Fi and mobile phone radiation	29.1% (23)	59.5% (47)	6.3% (5)	6.3% (4)	Subject of this article; however there is no evidence to support this statement.
Male circumcision is unnecessary	79.9% (63)	13.9% (11)	3.8% (3)	2.5% (2)	Current medical research supports this statement.
Cancer can be caused by a virus	48.6% (36)	35.1% (26)	1.4% (1)	14.9% (11)	Cervical cancer is caused by HPV, this statement is true.

Table 1: Overview of responses to an informal and anonymous survey of 80 associates, most of whom work in science or an allied industry

	Total comments citing mass media / rumor / friend-of-a-friend etc.	Total comments citing professional option / research / review / evidence	Total (not all respondents cited media)
Spinach contains loads of iron and is particularly good for you	61% (17) *	25% (7)	28
A diet containing a lot of fat is unlikely to be very healthy	27% (7)	15% (4)	26
Some routine childhood vaccinations are sufficiently risky to make me not want to give them to my children	50% (5)	0% (0)	10
Some people are made ill from Wi-Fi and mobile phone radiation	92% (11)	0% (0)	12
Male circumcision is unnecessary	8% (1)	62% (8)	13
Cancer can be caused by a virus	21% (4)	26% (5)	19

Table 2: Types of communication mentioned by respondents as influencing opinion

\* 8 respondents specifically refer to Popeye or “decimal point error”