#### **Supplying the Evidence**

Iain Chalmers, James Lind Initiative and Testing treatments.org

I write this as a doctor who has done harm.



# Fund raising advert for the United Nations Association, 1968

Figure 1

The picture in Figure 1 was taken in 1968. I was paid £20 [Approx. £250 2014 equivalent] for modelling. They put the title on, 'this doctor needs your help'. It was a fundraiser. You know he's a do-gooder because he's got a stethoscope.

I went from there to the Gaza Strip, to a refugee camp for a couple of years. It was there that I found how easy it is for do-gooders to do harm. Basically this underlies everything I've got to say here. I think it is very important that a higher proportion of the population become better bullshit-detectors when it comes to treatment claims. Because without that, people are still going to suffer and sometimes die frequently.

#### Harm resulting from insufficiently critical clinical practice



Figure 2

Figure 2 shows the cover of a book I bought it in 1965. As you can see, 19 million copies had been sold at that time. The baby on the front cover is lying on his front. This may be partly because Dr Spock said this: 'It is preferable to get a baby accustomed to sleeping on its stomach from the start'.

I had actually marked that passage because it was something I needed to communicate while I was a doctor to the parents. We now know that led to a veritable holocaust of crib deaths, sudden infant deaths. The estimate is that probably at least 10,000 died in the UK alone.

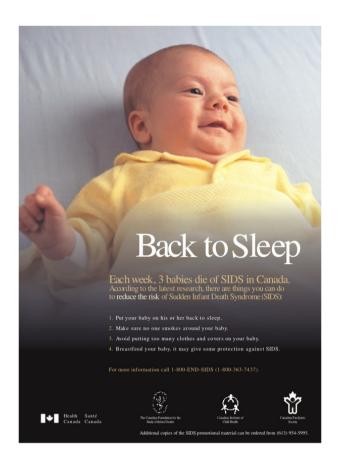
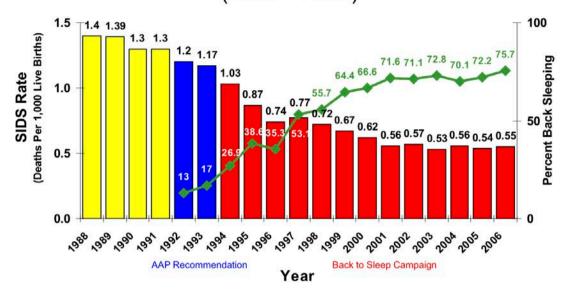


Figure 3

Eventually we got around to recognising that this advice, which wasn't based on any empirical research, it was based on theory, was wrong. 'Back to sleep' campaigns (Figure 3) were funded in a number of countries. Anne Diamond, a television presenter, whose son had actually died a suddeninfant death, was one of the people who made me take notice of this new message. What we saw was the rate of sudden-infant deaths falling as the change in sleeping position grew more common, to back lying (Figure 4).

## SIDS Rate and Back Sleeping

(1988 - 2006)



SIDS Rate Source: CDC, National Center for Health Statistics, Sleep Position Data: NICHD, National Infant Sleep Position Study.

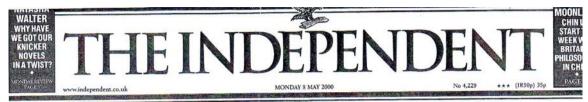
Figure 4

That's an example of the way that something as apparently innocuous as medical advice can have lethal effects. This is not talking about adverse reactions from drugs or surgical procedures and so on, this is about advice.

#### Harm resulting from insufficiently critical journalism

A couple of examples, both of which I know a little bit about but I knew a lot about the first one.

### A media 'feeding frenzy'



# Parents were misled over hospital trials that killed premature babies

## Hospital condemned over experiments on babies

These failures reflect badly on the medical profession

A disturbing tale and a host of ugly conclusions

### Babies and consent: yet another NHS scandal

Figure 5

The story illustrated in Figure 5 concerned not Mid Staffordshire but North Staffordshire. It started off with a local story in a local newspaper. This was concerning a control trial designed to find out if there were better ways of helping the babies that needed help with breathing after premature delivery, whether they could be helped using another approach. There were good reasons to think it might be better.

What happened was the people who were doing this study were being attacked by a lobby group for a completely different part of their work, which was child abuse. And these headlines give some sort of feeling of just what a feeding frenzy some journalists, including the editor of the BMJ, came to swallow about this study and the people who did it.

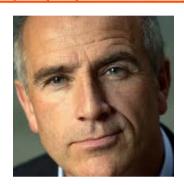
Can you imagine an editor not feeling, because he was challenged by the parliamentary committee, that he might have been wrong to say parents have been misled over hospital trials that killed premature babies, that the trials killed the babies? It led to a regional inquiry (the Griffiths Inquiry) which led to a new national framework for approving and monitoring research projects. The consequence of that was the strangulation of needed research.

## THREE DOCTORS AND THE GMC

Following the collapse of a GMC case involving neonatal research that took 15 years to come to a hearing, **Jonathan Gornall** has uncovered a trail of incompetence and maladministration

BMJ 2008;337:258-61

The cloud that since 1997 had hung over the heads of David Southall, Martin Samuels, and Andrew Spencer and, by association, everyone at the two centres that had participated in the trial of continuous negative extrathoracic pressure (CNEP) as a treatment for neonatal respiratory failure, had been lifted.



**Jonathan Gornall** 

#### Figure 6

It wasn't until Jonathan Gornall (Figure 6) looked into this story in detail and documented that the whole thing had been manufactured for quite other reasons, to get at doctors and nurses who were involved in child protection work, that the truth came out. After 11 years the doctors were completely exonerated by the General Medical Council. Jonathan Gornall deserves whatever prizes you get in journalism.

#### Early report

## lleal-lymphoid-nodular hyperplasia, non-specific colitis, and pervasive developmental disorder in children

A J Wakefield, S H Murch, A Anthony, J Linnell, D M Casson, M Malik, M Berelowitz, A P Dhillon, M A Thomson, P Harvey, A Valentine, S E Davies, J A Walker-Smith

Lancet 1998; **351:** 637–41 See Commentary page 611

Inflammatory Bowel Disease Study Group, University Departments of Medicine and Histopathology (A J Wakefield Frcs, A Anthony MB, J Linnell PhD, A P Dhillon MRCPath, S E Davies MRCPath) and the University Departments of Paediatric Gastroenterology (S H Murch MB, D M Casson MRCP, M Malik MRCP, M A Thomson FRCP, J A Walker-Smith FrcP,), Child and Adolescent Psychiatry (M Berelowitz FrcPsych), Neurology (P Harvey FrcP), and Radiology (A Valentine FrcR), Royal Free Hospital and School of Medicine, London NW3 2QG, UK

Correspondence to: Dr A J Wakefield

#### Figure 7

Figure 7 shows a more famous story: Andrew Wakefield's paper in the *Lancet* which led people to claim and him to make money out of the idea that MMR vaccine led to child autism. That led to an epidemic of measles in the UK. I say that the primary cause was parents being in desperate need to find a culprit for their child's autism. But there was research fraud which wasn't picked up. There were undeclared conflicts of interest that were not picked up by the *Lancet*. There was failure of critical appraisal and uncritical, sensationalist journalism.

The *Daily Mail* was responsible for promoting this idea (for examples see Figure 8). How was it revealed? Not by my profession, by your profession, by Brian Dear writing for the *Sunday Times*. Who got to the bottom of it and that resulted in the doctor concerned being struck off and the paper being retracted.





#### Figure 8

I've given examples of ways which I have helped to kill people, that journalists have helped to kill people. The good journalists who followed those two stories were exemplary because they got to the bottom of them.

Andy Williams, who is in the School of Journalism in Cardiff, sent me slides summarising the results of the research that he's done. There's more work to cope with, less time to check facts and research stories, it has been suggested that science journalism is becoming de-skilled and that the content that you see in the newspapers is more homogenous, and that the sources of the stories are pretty powerful.

### Research press releases need better policing

Blaming the media for bad reporting is good sport. It's easy to find headlines in the broadsheets as well as the tabloids breaking health news with overstated research findings.

Caveats of scientific conclusions are often abbreviated or absent. Scientific uncertainties can be left diminished or invisible.

The media have been repeatedly blamed for misinformation and health scares, and no wonder: when patients voice or act on misconceptions in the press, trying to redress the balance can eat up scarce clinical time.

I confess a previous secret pleasure in playing the dissing bad headlines game. My own crossness with bad health reporting was the reason I started writing. But the rules were never fair, I now realise.

Doctors and scientists are expected to be trustworthy, and journalists may reasonably assume that press releases present the facts fairly, unambiguously, and without spin. For a few chosen authors, media officers at universities or journals



The press release encouraged "yoga, meditation and mindfulness" despite the study considering none of these interventions

#### bmi.com

 Read Margaret's recent BMJ Confidential (BMJ 2014;348:g2015)

#### Twitter

@mgtmccartney

will decide their paper is worthy of a press release. It will be sent out under embargo, before the research is published. The aim is to generate interest in the paper.

A typical press release will contain a summary of the paper, a few statistics aching to be used in a headline, and some quotes from the authors. Some include access to the full paper; but others don't.

The result can be bad reporting. For example, when the press release's first line says, "Eating 7 or more portions of fruit and vegetables a day reduces your risk of death at any point in time by 42%" and that the effect was "staggering," no wonder the press bounced "42%" around, and the BBC used the headline, "Seven-a-day fruit and veg 'saves lives'." But this study was capable only of finding association and not causation.

And then there are postulated add ons. For example, in a study that found higher salivary concentrations of one of two possible markers for stress in women trying to conceive, the author in the press release encouraged "yoga, meditation and mindfulness" despite the study considering none of these interventions. 6

The CONSORT (Consolidated Standards of Reporting Trials) guidelines have been successful in improving the reporting of randomised controlled trials. Tet we know that the public still miss out:

half of press releases on randomised controlled trials get spun.<sup>8</sup> We urgently need to ensure the public get better information about medical research. We need guidelines for press releases.

Research should be placed in context, caveats made crystal, limitations defined, and the meaning of an association spelled out. And relative risks should be banned forthwith.

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References are in the version on bmj.com. Cite this as: BMI 2014:348:g2868

#### Figure 9

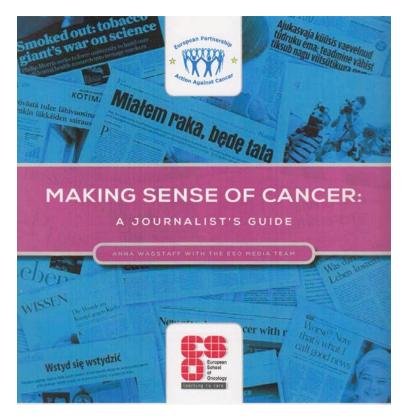
Margaret McCartney, who is writes for the BMJ but also writes elsewhere, is a general practitioner, starts off in the recently published piece in Figure 9 by admitting herself that she thought that sloppy journalism was fair game. And that she confesses to a secret pleasure in playing the dissing bad headlines game. But then she looks at the evidence of where these headlines are coming from and where the stories are coming from. Too often, they are coming from press releases by institutions and individual researchers, insufficiently challenged. Those people who issue the press releases have got vested interests.

#### Solutions?

I don't know what the solutions are. Figure 10 shows one example: Anna Wagstaff's recently published guide for journalists, *Making Sense of Cancer* 

(http://www.cancerworld.org/cancerworld/images/file/Media Guide single%20pages indice.pdf).

I've read the bits that relate to testing treatments which I know more about. It's fantastic. It's very, very good indeed. Is that going to help cancer journalists? The work needed to produce it wouldn't have been done if there hadn't been a hope that it would be useful.



By Anna Wagstaff with the ESO Media Team

Figure 10

Might *Testing Treatments Interactive* (www.testingtreatments.org) be helpful to journalists? The idea behind the books from this, which this went into two editions, is motivated by the belief that unless people become better bullshit detectors people are going to suffer and die unnecessarily. That is the motivation for trying. This may not work. We've wondered who our possible users are, it's quite a young database.

#### How can I get fact-checks of health news?

If you don't have the time or skills to do a full fact-check yourself, there is a range of trustworthy sources of evidence-based analysis of current health news stories.

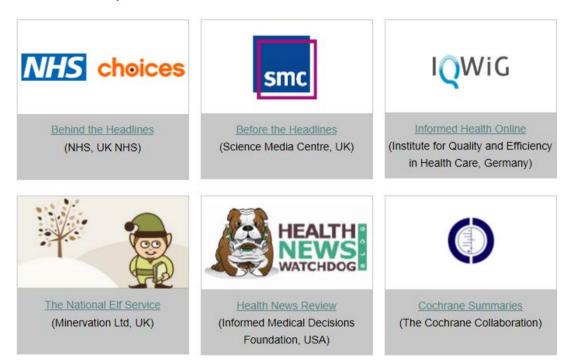


Figure 11

Figure 11 shows a section we've put together for journalists. We've already had input about the sort of things that might be useful in one place.

#### Where can I find trustworthy information?

Finding reliable, user-friendly sources of information about clinical conditions and treatments can be difficult. We recommend regular doses of the following:

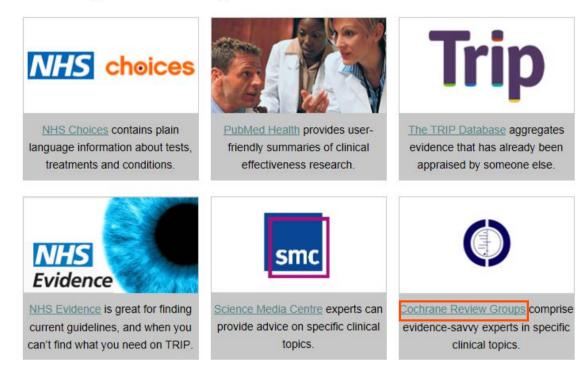


Figure 12

Figure 12 shows something which in discussion with the journalists we have been talking to seemed to be useful. I think journalists are often using quotes from an expert as part of the stories that they write. They don't have the to go and find out what conflicts of interest there may be from the people who they're inviting to comment. So we've put a direct link to the contact details for all 50 Cochrane systematic reviews, the Cochrane editorial bases. Because the Cochrane Collaboration doesn't take money from industry. In fact it polices rather rigorously anyone who is conflicted in that way. I hope that that may be one resource to which journalists might find helpful given the pressures upon them. These groups are all over the world. But each of them has usually hundreds of people contributing to their work so they have a lot of mailing lists which might be sources to guide people to those they feel would give them a good assessments, particularly with treatment claims.

## Medical messages in the media – barriers and solutions to improving medical journalism

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**Design** We reviewed the literature and organized focus groups, a survey of medical journalists in 37 countries, and semi-structured telephone interviews.

**Conclusion** Medical journalists agree that the validity of medical reporting in the mass media is important. A majority acknowledge many constraints. Mutual efforts of health-care professionals and journalists employing a variety of strategies will be needed to address these constraints.

Health Expectations, 6, pp.323-331

#### Figure 13

Figure 13 shows something I felt that might be of interest. But I go back to the main point. It's all about trying to reduce unnecessary suffering and death. That, as far as I am concerned, must be the dominant consideration.