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Newsletter 92 January 2014

A FULL HOUSE AT 2013 AGM

THERE WAS an extra feeling of excitement at this year's HealthWatch annual general meeting. Without question this was stirred by the presence of our awardwinner, the *British Medical Journal*'s editor-in-chief Fiona Godlee.

The subject matter of her talk, "What's wrong with the medical literature and what can we do about it?" went to the heart of some of the issues that most concern HealthWatch—bias in reporting of clinical trials, the need for transparency, and the dangers of overdiagnosis and overtreating. Modern medicine is fortunate to have such a voice, and we were privileged and delighted to hear her at our meeting. You can read more about Dr Godlee's talk on pages 4 and 5 of this issue (with a full transcript on our website **www.healthwatch-uk.org**).

She spoke to what is possibly our largest AGM audience ever. Almost every chair at the Medical Society of London was filled, and we were pleased to welcome back some of our previous years' awardwinners, including Iain Chalmers, Michael Baum, Peter Wilmshurst and Annabel Ferriman. Joining us for the first time were friends from organisations who share many of our aims, Sense About Science and the Nightingale Collaboration, as well as the patron we share with Sense About Science, Lord Dick Taverne. Thanks are due to the Medical Journalists' Association for their help in promoting this year's AGM.

As on previous years, there was a warm welcome for winners of the 2013 HealthWatch Student Prize, about whom there is more on page 3 of this issue. HealthWatch thrives on the balance between the wisdom and experience of our long-standing members with a regular injection of youth and new ideas. We came away revitalised, with high hopes for what we will achieve in 2014.

Fiona Godlee receives the 2013 HealthWatch Award from Nick Ross

HealthWatch research published in FACT

A MANUSCRIPT reporting on what may be the first survey of UK medical students' experience of complementary and alternative medicine (CAM) teaching has been published in the December issue of the journal *Focus on Alternative and Complementary Therapies* (FACT), together with an editorial by Dr David Bender.

More information about the editorial and the paper, which was authored by a team from HealthWatch, can be found on the HealthWatch website **www.healthwatch-uk.org**

With substantial public interest in CAM therapies, future doctors will be expected to provide evidence-based advice on their safety and efficacy, hence the need to ensure medical students are informed and able to evaluate the therapies. Ninety-three students from 25 different medical courses responded to the 10-question survey, which invited them to report on the numbers of lectures on CAM and statistics they had received, and rate the teaching and quality of feedback after CAM placements.

Just over half the students reported that they had received lectures on CAM in the core course, fewer than 50% of whom said the lectures were critical and evidence-based, as opposed to "uncritical" (16%) or "discursive" (39%). Of 33 students who reported that they had had placements with CAM practitioners, more than half stated that they had received no feedback on the placements. The study authors call for UK curriculum coordinators to review the teaching of CAM-related components in the courses.

In his editorial David Bender expressed concern that only half the teaching about CAM in the core course was appropriately critical, applying principles of evidence-based medicine, and that over half the students who had been placed with a CAM practitioner had not received any formal feedback on their experience.

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IT'S YOUR TURN TO ASK FOR EVIDENCE

INCLUDED WITH the printed issue of this *HealthWatch Newsletter* you will find your "Ask For Evidence" postcard. Please use it!

HealthWatch is supporting the Ask For Evidence campaign being run by Sense About Science, the charity that aims to equip people to make sense of claims in all areas of science as well as medicine.

"Every day, we hear claims about what is good for our health, bad for the environment, how to improve education, cut crime, and treat disease," says SAS campaigns and policy officer Chris Peters. "Some are based on reliable evidence and scientific rigour. Many are not. These claims can't be regulated; every time one is debunked another pops up—like a game of whack-a-mole. So how can we make companies, politicians, commentators and official bodies accountable for the claims they make? If they want us to vote for them, believe them, or buy their products, then we should ask them for evidence, as consumers, patients, voters and citizens."

So, if you want to challenge whether a claim made in a policy, newspaper article, advert or product is backed by scientific evidence, use your postcard to Ask for Evidence. For more postcards, an online form, or to read about how others have fared in their requests for evidence, visit Sense About Science's website at: **http://www.senseaboutscience.org/pages/a4e_postcard.html**

All in the name of health

AS MEMBERS ARE by now aware, in October 2012 the UK government launched an initiative which has resulted in considerable confusion for HealthWatch. "Healthwatch England" is the name for the "independent consumer champion for health and social care in England", and comprises a network of 152 local Healthwatch groups.

Because one of Healthwatch England's aims is to collect consumers' views and experience in order to help shape and improve local services, it was not long before our own press enquiries hotline was inundated with calls from people wishing to complain about local health services. Because of the time and effort involved in handling these, it became necessary to close down our hotline and rely instead on an e-mail address for media enquiries.

(It's a two-way street however, as we are no doubt gaining Twitter followers who believe we are Healthwatch England).

At a recent HealthWatch Committee meeting it was suggested that we invite members to offer their suggestions as to how to deal with the confusion. Should we have a new name? Or a more readily distinguished strapline (we currently use "for treatments that work"). One suggestion is "Promoting evidence in healthcare since 1991".

If you have views or suggestions please don't hesitate to send an e-mail to **enquiries@healthwatch-uk.org** Thank you.

NEWS IN BRIEF

WE CONGRATULATE David Nutt, who has won the 2013 John Maddox Prize for Standing up for Science in recognition of the impact his thinking and actions have had in influencing evidence-based classification of drugs, in the United Kingdom and elsewhere in the world, and his continued courage and commitment to rational debate, despite opposition and public criticism. David Nutt is professor of neuropsychopharmacology at Imperial College London.

http://www.senseaboutscience.org/pages/maddox-prize-2013.html

EXPERIENCING side effects is unpleasant, and not understanding them is frustrating. While it's impossible to have a drug with no side effects, a new guide demystifies why they happen and what can be done about them. Making Sense of Drug Safety Science: Investigating the science of side effects also shares insights into how the yellow card system works, and opens up clinical trials. The guide was produced in collaboration with the MRC Centre for Drug Safety Science with support from the MRC.

http://www.senseaboutscience.org/pages/making-sense-of-drug-safety-science.html

IN NOVEMBER the medicines regulator (MHRA), signaled its desire to bring to an end the 40-year anachronism of homeopathic Product Licences of Right (PLRs), which have allowed homeopathic products to be exempt from the standards demanded of other products classed as medicines. According to data obtained under a freedom of information request by the Nightingale Collaboration, there are 406 PLR products, most of which are homeopathic. Under new rules, their manufacturers will have to transfer the PLR products to either the Simplified Registration (HR) Scheme—under which they will not be allowed to say what medical conditions they may be used for, and will have to carry the text: "Homeopathic medicinal product without approved therapeutic indications"; or the National Rules (NR) scheme, which will require 'evidence' for therapeutic use. In practice, evidence for NR may be as superficial as evidence of previous use for an indication, or an unscientific 'proving'. "However, this means they are brought under control to some extent and are more tightly controlled in terms of advertising," comment the Nightingale Collaboration. "Unfortunately, the MHRA has not given a deadline," they add.

http://www.nightingale-collaboration.org/news.html

A REPORT ADDRESSING concerns about the inappropriate use of non-validated pathology tests in Australia has been presented to the country's health minister. The Friends of Science in Medicine (FSM) Pathology Advisory Group prepared the guidelines to protect patients from being misled by unproven tests, e.g., when offered by unscrupulous practitioners as a means of marketing their own services. Tests covered include, 'live blood analysis', 'clot retraction tests', 'Vega tests', 'electro-dermal screening', iridology and kinesiology testing, marketed directly to the public or sold by alternative practitioners. FSM's final advisory paper has the support of The Royal College of Pathologists of Australia, and makes recommendations on the accreditation of laboratories conducting the tests, the qualifications of the practitioners who order them and the rights of patients. They now await the Australian Federal Government's response to the guidelines. FSM began as a group of Australian academics who were alarmed at the growth in teaching of non-scientific health courses colleges and universities, and now has over 1,000 members globally.

http://www.scienceinmedicine.org.au/images/pdf/newsletter07.pdf

A YEAR OF SURPRISES AND GROWING INFLUENCE

HealthWatch chairman Keith Isaacson addressed our biggest AGM audience ever at the Medical Society of London, on Thursday 24th October

THIS YEAR started with the most exciting surprise announcement that an anonymous donor had given HealthWatch £50,000 for research projects that had aims related to our charity. The requirements and legal documents have been prepared. It has been decided that it should be allocated in amounts of up to £10,000. We are keen to promote this grant and are pleased that the first application has been granted, and it will be used to extend Les Rose's study on trading standards.

In the spring we had a public meeting which involved all three of our then new patrons. Professor Steve Jones and Sir Michael Rawlins each spoke on the topic: "The Direction of Medical Research: Top Down or Bottom Up?" Sir Michael had only flown back from America that morning. The meeting was chaired by Robin Ince. Thanks to Debra Bick and her team, we were able to hold the meeting at Kings College London. Over 100 attended and it was an excellent evening.

You can now watch a video of the proceedings on this link: **http://www.healthwatch-uk.org/video-of-healthwatch-lecture-available/**

The study on the teaching of Complementary and Alternative Medicine to medical students carried out by our two student members Derek Ho and Kenneth Chan has been accepted for publication in FACT. The follow up to this study, a questionnaire, was sent to all the Deans of the UK medical schools to determine if the teaching of CAM was subject to critical analysis. I was astonished to find that there are 31 schools. I personally signed and sent a letter to all 31 Deans. It was extremely disappointing that only five of them replied.

We are delighted that one of our former award winners, Dr Margaret McCartney, has accepted our invitation to become a Patron. She sends her apologies for tonight's meeting.

I appreciate the help that I get from all the members of the committee, especially David Bender the secretary.

One of our student members Derek Ho has qualified in medicine and we congratulate him and hope he will be able to continue as a trainee doctor committee member.

Mandy Payne our editor has returned to live in England and she is now able to attend our committee meetings at which her input is invaluable. We really appreciate the work she puts into the Newsletter and our Twitter account that she now runs, fitting this into her other work commitments. As ever we are extremely grateful to our barrister Caroline Addy who checks each issue of the newsletter for potential libel issues before it goes to print.

We are losing two Committee members this year, both of whom have other busy commitments: Gillian Robinson and Walli Bounds. They have both put in many hours of their time to run the student prize and we hope that they may continue to do this. Walli has been on the committee since the inception of HW and we will greatly miss her research expertise.

Nick Ross our President keeps his finger on the pulse of medical matters. His media contacts are invaluable.

Keith Isaacson

UCL's student prize hat-trick

THREE OUT OF this year's four winners of the HealthWatch Student Prize were from University College London, so they didn't have far to travel to collect their prizes from Nick Ross.

Joint first prize for medical students went to Dylan Mac Lochlainn (UCL) and Claire Wood (University of Glasgow). Dylan, aged 22, from Drumquin, County Tyrone, is in the 5th year of his degree. Newly graduated Claire, 25, of Stirling, was not able to attend the meeting. From the professions allied to medicine came two more UCL students Henry Lancashire, aged 24, originally from Bury St Edmunds, and Shuchang Liu, 25, from Beijing, China—biomedical and biochemical engineers respectively.

All four excelled in their entries, and we extend our admiration and congratulations to them.

Reviewing this year's competition, Walli Bounds noted that only seven entries were received from nursing and allied professions. As nurses are often asked by the public for advice about medical issues, their need for training in evidence-based medicine is acute.

With the exception of the winners, among entries who had placed the protocols in the correct order, the explanations of why they had done so, and identification of serious flaws in some of the protocols, was disappointing—many failed to spot the lack of ethics committee approval or informed patient consent, other entries failed to notice absence of a control group or assessor blinding. For this reason, there were fewer runners-up this year.

HealthWatch is most grateful to Professor John Garrow for his generosity in providing the funding for the 2013 competition. We extend our thanks to Cambridge University Press for having generously agreed to sponsor the competition from 2014, and to Professor David Bender for his help in securing this funding.

HealthWatch Student Prizewinners, from left to right: Dylan Mac Lochlainn, Shuchang Liu, Henry Lancashire

WHAT'S WRONG WITH THE MEDICAL LITERATURE AND WHAT CAN WE DO ABOUT IT?

Fiona Godlee, editor-in-chief of the British Medical Journal, received the HealthWatch Award at our 2013 annual general meeting at the Medical Society of London on 24th October

THE *BMJ* has for a long time been a campaigning journal, and that is something we are continuing. I'd like to talk about two campaigns in particular tonight. One is, open access to clinical trial data, and the other is "too much medicine", which again fits very well with HealthWatch's aims. This is one of many areas in which we find that the evidence base is distorted, and it ends up pushing us to overtreat and overdiagnose—there is this conspiracy of enthusiasm for treatment which I think as medics we have to constantly rein ourselves back on.

We have a problem. We want to practice evidence based medicine, but the evidence on which our decisions are based is flawed. It is incomplete and it is of poor quality and based on hidden data. There is a huge loss of trust. There have been too many examples of bad practice, bad faith and out-and-out misconduct, especially but by no means only on the part of industry, over the past 30 years or so. Journals must accept a good chunk of the blame, as must the medical profession, and the research establishment. So we've got growing evidence of the problem of misleading, misreported, incomplete data. We've got hidden trial data, and the tendency that this distortion has to lead us to over diagnose and over treat, which is how these two campaigns find themselves coming together.

There was a review in 2010 in the journal Trials,[1] done by Germany's IQWiG group (the German equivalent of the UK's NICE), and they looked at a huge number of conditions, and found under-reporting and misreporting of trial data across the entire array of medicine. No method was spared. The problem was very much associated with pharmaceutical company trials, but also non-pharmaceutical company trials, and overwhelmingly they found evidence of benefits being over-stated and harms being understated. In addition we now know that only about half of clinical trials end up getting published[2] and the US legislation, the 2007 FDA Amendments Act that everyone felt was such a great thing, and *is* a great thing, is being widely ignored, in the sense that the summary data that is supposed to be published within a year of the study finishing, is not being published within that time frame.[3] So we've got things in place which should be helping, but they're not.

I'll give you two examples. The 'flu pandemic of 2008-9 gave Roche's drug Tamiflu an enormous boost. Initially a Cochrane review found it was effective in reducing the complications of influenza, such as pneumonia.[4] The Cochrane team were asked to update their review, they thought it would be a simple job, just looking at the most recent trials and most likely coming to the same conclusion, but a Japanese pediatrician had noticed that actually the data on which their review was based was entirely industry-funded, that out of 10 trials that had been summarized in an industry-funded systematic review, only two of these had been published in peer-reviewed journals, the other eight were apparently either unpublished or published only in abstract form.[5] Now these Cochrane reviewers, being the people they are, asked the industry funded reviewer if they could see the data, and were told, "You'll have to go to the authors of the original trials." Those authors in turn sent them to the drug company, who said, "We can't give you this." At which point they came to the *BMJ* and Channel 4, and we had some articles about this.[6] Interestingly, while the European Medicines Agency has approved the label claim that Tamiflu reduces the complications of influenza, Roche's US website says, with a footnote pointing out that the advice is for American audiences only, that it is *not* proven to reduce complications.[6] So you've got the same evidence base but the authorizing bodies have come to completely different conclusions.

But what is deeply shocking is that this drug, on which governments are spending billions of pounds, is apparently not yet proven to be any better than paracetamol and may have adverse effects. Moreover, the evidence base on which these decisions are being made is entirely in the hands of the manufacturers of the drug.

Thanks to Ben Goldacre's book[7] and the huge interest that caused, and building on the work that Iain Chalmers has been undertaking, we are making progress. The AllTrials campaign,[8] the BMJ's "open correspondence" page,[9] which has been publishing letters between the Cochrane Collaboration and Roche, and likewise similar activities of the Cochrane Collaboration with GlaxoSmithKline, WHO, and so on, are slowly making an impact. GSK have distanced themselves from the pack and have made some very important concessions.[10] Now Roche, four years after their original promise to make their data available, have done so.[11] We hope that we will soon know the truth about Tamiflu. It may be marvelous, we will have to wait to see—the Cochrane Collaboration are planning to publish their revised review in a few month's time.

The next case is the antidepressant Reboxetine, which used to be quite widely used. Germany's IQWiG was going to re-license it, in order to keep it on the list of drugs that are reimbursed by health insurance companies, and they asked the drug company Pfizer for the data, and Pfizer said, "No." So they said, "If we can't review the data, we can't keep your drug on the list. It turned out, when they finally gave up the data, that about 65% of it had never been published. When they took the unpublished data and considered all the data together they found that a drug which was previously considered effective and safe, actually had no benefit.[12]

The difficulty we have is that we just don't know how much of the current evidence base is similarly flawed.

It is not just industry that is at fault. If you have a melanoma you may end up having your lymph nodes dissected out and the procedure, sentinel node biopsy, is invasive and can result in complications. A study in the *New England Journal of Medicine* published five year results of the Multicenter Selective Lymphadenectomy Trial (MSLT-I) and these data suggested any survival advantage was marginal. They were supposed to publish 7-year data, then 10-year data, but the dates for those publications has passed and the authors are not coming up with the goods. We published an article saying this is a problem, people are having this procedure and the data are not available.[14]

So it's not just industry who are doing this. It is, however, true to say that industry is the largest funder of pharmaceutical trials, and the funder with what we can only call an irreducible conflict of interest. They are there to make money for the stakeholder and, ideally, also to help patients, but that is their conflict of interest which

they will never escape.

Things are changing, but it's not yet solved. One drug company, AbbVie, which produces a drug called Humira for arthritis, is suing the European Medicines Agency to stop them making the summary data around their drug available, and the European Federation of Pharmaceutical Industries and Associations, of which AbbVie is a member, is supporting AbbVie in this.[15] AbbVie's lawyer has made clear that the company considers even data on adverse events to be commercially confidential. There's no doubt that patient confidentiality is one issue, there are many others, but we can get through them. In fact a lot of the time, if you look at individual examples of information that people are saying they can't share, it's actually already being shared, so it's not always as much of a problem as it's being made out to be.

I expect many people in this room are on statins. The current guidance is to prescribe statins if your 10-year risk of cardiovascular disease is more than 20%. It scoops a lot of people onto these drugs, at enormous cost to the health service and with an enormous revenue for the industry. Last year the Cholesterol Treatment Trialists (CTT) Collaboration published in the *Lancet* an enormous meta-analysis of individual patient data, which concluded that people at even lower risk could benefit from statins,[16] and that led to the suggestion that maybe everyone over the age of 50 should be on these drugs. Now a paper in this week's *BMJ*[17] questions that. This new analysis of the data doesn't find an overall reduction in mortality, and it also says that none of the trials in the meta-analysis really looked at harms—and statins can cause diabetes, myopathy, and there are all sorts of minor effects along with some serious harms. They also point out that all the trials in the *Lancet* meta-analysis are funded by the producer of the statins. Usefully the *BMJ* paper also lists what low risk patients need to know, and top of the list is the need for lifestyle change. This, in a society dominated by pharmaceutical-funded research, is something that tends to be underplayed and obscured.

WHICH LEADS ME on to "too much medicine". A long-standing interest of the *BMJ* is over-diagnosis and over-treatment—why does it happen? The reasons are very complex: more and more sensitive diagnostic technology, finding that little thing that would otherwise go unnoticed; increased patient expectations; the belief that more medicine is better medicine. And then some less worthy reasons: personal financial gain; doctors paid for doing more, the so-called "fee for service"; commercial gain by drug manufacturers and medical device companies; a change in diagnostic criteria so more and more people are labeled as being at risk of or actually having a disease; and conflicted guideline panels, so that those diagnostic criteria are being decided on by people with conflicts of interest.

So it's no longer just diabetes and hypertension and dementia but we've now got pre-diabetes, pre-hypertension, pre-dementia—for which good evidence is lacking but increasing proportions of the population are encouraged to have monitoring and preventive treatment, all of which has side effects, and all of which has costs.

The poster child for overdiagnosis is perhaps breast cancer screening. We're just beginning to understand why this is a real risk for women, and Michael Baum has been a great advocate for a much clearer understanding of those risks. Thyroid cancer is an example that has received less publicity. It's one of those cases where you detect something and, of course, it's very hard to leave something there once you've found it, but after surgical removal come all the other problems of treatment—thyroid monitoring, radiation to the neck, and so on. So it's not just one procedure, it's a lifetime of taking drugs, and being a patient in a way that you wouldn't otherwise have been.

The list of things we want is long. The meat of it is captured this week by Richard Lehman in his journal review blog in the *BMJ*. He is often critical of industry and of the types of studies being published. Here is his very brief solution:

"All phase 3 trials to be designed and conducted independently of manufacturers, using the best available comparator. Research priorities to be determined by patients (James Lind Alliance). Value-based pricing. All data available from all trials, with meta-data: IPD [individual patient data] level for qualified independent centres. Big increase in comparative effectiveness research, much more research into non-pharmacological treatments."[18]

In conclusion, the evidence base is clearly flawed. Research is a human activity—we can't expect perfection, but we are so far from perfection and there's a great deal more to do. I have reached a firm conclusion, and I am not alone in concluding, that there is a need to extricate medicine and research from industry. It will be a challenge.

Fiona Godlee
Editor in chief, British Medical Journal

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The full text of Dr Godlee's presentation is available on our website www.healthwatch-uk.org

BALANCE IN HEALTH REPORTING - AN IMPOSSIBLE DREAM?

This article by John Illman is adapted with the author's kind permission from his article published in The Microbiologist*, December 2013 issue (see below for full reference).* The Microbiologist *is published by the Society for Applied Microbiology and available from* ***http://www.sfam.org.uk/en/news-features/microbiologist/***

THE MEDIA is alleged to create health scares to provoke panic and banner headlines. There is sometimes some truth in these accusations, but the head-on collision between two of the biggest drivers in contemporary life—science and preoccupation with risk—has created what the sociologist Frank Furedi calls a culture of fear.[1] Previous generations did not ask: do mobile phones cause brain cancer? Should we take aspirin to avoid heart attacks? Should we vaccinate our children? The media did not create this culture, but it does fuel it.

However, the media is primarily reactive, not proactive. A study of medical journals in Scandinavia and the UK between 1967 and 1991 found a highly significant increase in the use of the term 'risk'.[2] During the first five years the number of 'risk' articles published was about 1000—for the last five years there were over 80,000. The media should and did reflect this trend.

During the same period the relationship between doctors and patients changed and people became increasingly interested in their health. Again, this was not because of the media, but because of the impact of consumerism, self-help groups, the women's liberation movement which campaigned against the medicalization of everyday life and the HIV/AIDs lobby which provided a template for thousands of advocacy groups for patients with diseases ranging from depression to breast cancer.

How has science, the biggest ever driver of change, changed? Ironically, researchers are still encouraged, as they were half a century ago, to remain at the bench and let their publications talk for them. However, the MMR story—in which a single (now discredited) research paper started a chain reaction that resulted in a dangerous fall in vaccination levels—is one of many examples exploding the myth that evidence speaks for itself. This may be especially true of vaccination, which has been controversial ever since Edward Jenner's pioneering work against smallpox in the early 1800s.

"I believe scientists over-estimate the power of statistics in mass communication. Research into what persuaded people to give to charity showed that the better statistically informed the potential donors were, the less money they gave."

Research suggests that scientists and healthcare professionals assume that the public will make the right healthcare choices if they are provided with information. But should this include emotionally charged stories of children being harmed by vaccination? I believe so, because vaccination is not risk-free. There were 24 government awards to vaccine-damaged children totalling more than £2 million in the ten years to 2013/14.[3] However, context is everything. Critics complain that the media has highlighted the plight of the tiny minority of vaccine-damaged children without stressing the benefits to millions. Yet, to quote one example, the £3 million campaign launched by the government in 2001 was widely reported.

I believe scientists, however, over-estimate the power of statistics in mass communication. Research into what persuaded people to give to charity showed that the better statistically informed the potential donors were, the less money they gave.[4] People who read a short emotional appeal about a hungry African child gave more than twice as much as those just saw raw statistics about threats to millions of Africans.

If case histories carry more weight than statistics, why not adopt more of a storytelling approach, combining case histories with statistics? Storytelling is an integral part of every culture. Stories help us—in a way that statistics cannot—to define ourselves and to compare ourselves with others, giving us a sense of perspective about our place in the scheme of things. No one recognized this better than the late children's author Roald Dahl who declared: "Not to vaccinate your child really is almost a crime."[5] Dahl knew the power of this sound bite. His message was reinforced by the death of his own daughter from measles at the age of seven before a vaccine became available. Hers is one of many powerful case histories.

BUT MEDIA case histories have their critics. For example, Professor Raymond Tallis complains about "the curse of the media anecdote" and the habit of giving appealing individuals with their moving stories at least as much credence coverage as unappealing data, of preferring faces to graphs and vox-pops to statistics".[6] The anecdote may be an imperfect tool, but communication via *p*-values and confidence intervals resonates with only a small minority. The real problem is not so much the anecdote, as its misuse. The challenge is in achieving balance—easier said than done.

Journalists are trained to present both sides of the story in the interest of objectivity and impartiality. This "balance" can work well in a political story in which a government minister and an opposition spokesperson have equal time or space. It may not work so well in science stories in which two opposite viewpoints are presented as if they are equal.

In Health, Risk and News: The MMR Vaccine and the Media, Tammy Boyce complains that what is missing from much of the coverage of the MMR story is any sense of the weight of scientific evidence which is firmly stacked on the side of the safety of the vaccine.[7] When examining balance, she adds, it is not just a matter of counting which side appeared more often. Balance is also influenced by the way journalists use scientific evidence. Boyce argues that by selecting equal numbers of scientists for and against MMR, journalists suggest that scientists and healthcare professionals overall are split on the issue when, in reality, the vast majority support MMR. Mark Henderson's book The Geek Manifesto: Why Science Matters,[8] a must read for any mass communication student, also

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Adapted from: Illman J. MMR and the media. *The Microbiologist* 2013;Dec:14-16.
John Illman's sixth book, Handling the media: communication skills for healthcare professionals, is due out in 2014.

Me Medicine vs. We Medicine: reclaiming biotechnology for the common good

By Donna Dickenson

Published by Columbia University Press, 9 July 2013. RRP £19.99 (304 pages, hard cover)
ISBN-10: 0231159749 ISBN-13: 978-0231159746

BY CONTRASTING unfounded claims for the benefits of personalised treatments with the synergistic value of public health programmes, Donna Dickenson gives an intriguing, big-picture view of recent developments in healthcare science.

Dickenson is professor emerita of medical ethics at the University of London, and research associate at the Centre for Health, Law, and Emerging Technologies at the University of Oxford. In "Me Medicine vs. We Medicine", she says she is keen to emphasise that she hasn't "automatically assumed that Me Medicine is bad and We Medicine is good". "I do my level best to give a balanced, evidence-based account," she says.

Nonetheless, few readers will be surprised by the conclusion she reaches as she makes a compelling argument for the need to distance science from "enclosures" based around individual or corporate interests. Some benefits, such as herd immunity, only arise from the cumulative action of a community, she points out. "Population immunity is itself a kind of cooperative, a form of collective wealth in which we all share and from which all of our children benefit," she says.

As well as unpicking the "soaring promises made by advocates of personalized medicine", she tackles the downsides for individuals and society of privately banked cord blood and personal enhancement technologies. She also looks in depth at how the public's perception of vaccination, in both the developed and the developing world, has changed over the past decades. She examines not just the story of the measles, mumps and rubella (MMR) vaccine, but also the more recently developed vaccines against swine flu and human papilloma virus. Framing the stories of these different vaccines within her framework of "me medicine" and "we medicine" leads to a thought-provoking discussion of the benefits and responsibilities of individuals and societies around vaccination.

Dickenson's unpicking of commercial interests in personalised genetics and direct-to-consumer genetic testing is particularly intriguing. She looks at the business models for these companies, and the contrasts between the way their position themselves to potential investors and to those providing samples for sequencing. She also suggests tobacco companies had a long running interest in genome sequencing in the hope of finding a gene identifying those at risk from smoking, and those who could smoke worry-free.

Dickenson pulls together a fascinating dossier of evidence for her case, and placing these within her framework sparks interesting new insights into many of the issues discussed. Even if she has done "level best to give a balanced, evidence-based account", she makes a strong argument for the need to step back from mindlessly assuming we must move further towards even-more personalised medicine, and to consider the synergistic benefits of public health programmes.

Tom Moberly
HealthWatch Committee Member

BALANCE IN HEALTH REPORTING - AN IMPOSSIBLE DREAM?

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highlights this legitimate concern.

How does a journalist achieve "balance"? I have been puzzling over this question for more than 30 years. The most difficult thing to do as a journalist is to present the evidence appropriately especially in science, which is inherently controversial. It is easy enough to report what you are told, but this is rarely enough. Evidence needs to be interpreted and spoken for, and it shifts and changes according to who is doing the interpreting.

In his widely acclaimed book Bad Science,[9] Dr. Ben Goldacre criticizes the media for poor reporting, especially over MMR. Much of what he says is true, but such attacks discourage scientists and clinicians from working with the media. Avoiding media questions for fear that they may exacerbate public alarm may open up the ground to commercial interests who exploit fear for profit; and to pressure groups who disseminate misleading information. Saying 'no' to a media interview request may mean your view will go unrepresented or be misinterpreted as meaning you have something to hide.

In 2003, Channel Five broadcast a hagiographic drama about Andrew Wakefield, the author of the now-discredited MMR paper, followed by a studio debate with the man himself. Many experts on public health, paediatrics, autism and vaccination refused to take part. This principled but misguided stand robbed viewers of the authority of those who were best able to challenge Wakefield before a huge audience. Healthcare professionals and scientists need to recognize that if they don't seize opportunities to speak up, they may be misrepresented or will not be heard at all.

John Illman
Medical journalist and author
John Illman Communications (media and presentation skills training)

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PERILS OF OPEN ACCESS PUBLISHING

I OFTEN THINK about the problem people have in determining whether a published research article is sound or not. It would be very easy for me to set up an apparently sound online journal to publish quackery and non-science. Let's call it the *Chiltern Journal of Biomedical Science*, because I am a biomedical scientist, and am sitting in my study overlooking the Chilterns Area of Outstanding Natural Beauty.

I could produce a list of very eminent scientists to be the editorial board—to be safe I might choose only those who are dead, and therefore cannot object to having their names hijacked to bolster the apparent importance of *CJBS*. I could claim that all papers are peer reviewed, and then used what has been called the RAPES (Random Assessment Process for Examination Scripts) to select papers for publication. For those who do not know the RAPES technique, the idea is that you go to the top of a staircase and throw the scripts down. They are awarded degree classes depending on which step they fall on. I hasten to add here that as far as I know no-one uses RAPES to mark university examination scripts. External examiners are given sample scripts to review, and most universities now insist on at least two markers assessing each script, and both writing comments on them, so scripts marked by RAPES would not pass scrutiny.

But my hypothetical *CJBS* may not be so far from the real world of the fringes of open access publishing.

In the January 2013 Newsletter, in an article about peer review, I wrote "… there are many journals out there, and invitations to contribute to open access journals come in my email at least once a week, so if I go far enough down the ranking of journals I will probably be able to publish more or less anything somewhere."

The *BMJ* recently[1] cited a report in *Science*[2] by John Bohannon, a journalist who'd submitted a spoof paper containing very obvious flaws, and with invented authors and affiliations, to 304 open access journals. It was accepted by 157, and rejected by only 98 at the time he wrote the article. In at least one case the paper was accepted by a journal in a very different field—surely the first thing an editor does on receiving a paper that has been submitted is to decide whether or not it is within the scope of the journal.

With each letter of acceptance of the paper was the expected invoice for an article processing charge—in one case as much as $3100. (The article processing charge is how open access journals work—unlike traditional subscription journals, the content is available free of charge to all readers, and it is the author, or the author's institution or funding body who pays the costs of editing, typesetting and on-line mounting and maintenance.) Needless to say, on receiving the letter of acceptance, Bohannon withdrew his paper. It would be interesting to see whether, had he allowed it to be published in one or more journals, others would have picked up the self-plagiarism of multiple publication.

To mix a metaphor, there are obviously many cowboys out there in the jungle. How am I to know whether the *Journal of Natural Pharmaceuticals* or *American Journal of Medical and Dental Sciences* (actually published in Pakistan), two of the journals named by Bohannon, are more scientifically sound than the *Chiltern Journal of Biomedical Science*? Hidden among the many perfectly respectable open access journals there could well be many that are no better than the type of email scams we all know about—the wonderful investment opportunities, legacies from distant relatives, refunds from tax authorities and pitiful emails from friends saying they have been mugged while abroad and can I please send them money to get home, all of which require the unwary to give away their bank, credit card and other details.

If I want to publish invented clinical trials, I now know that there are plenty of open access journals out there that will do so for very much less than the cost of conducting even the smallest experiment. I tremble at the thought that snake oil salesmen will start to publish in this way, since it would make their advertising very much more impressive than testimonials from satisfied patients.

David A Bender
Emeritus Professor of Nutritional Biochemistry
University College London

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