The urgent need for transparency in scientific communication

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The next 30 minutes of your life

Why do we need transparency?

What is transparency?

Will transparency be a panacea? May it make things worse?

The ingredients of trust

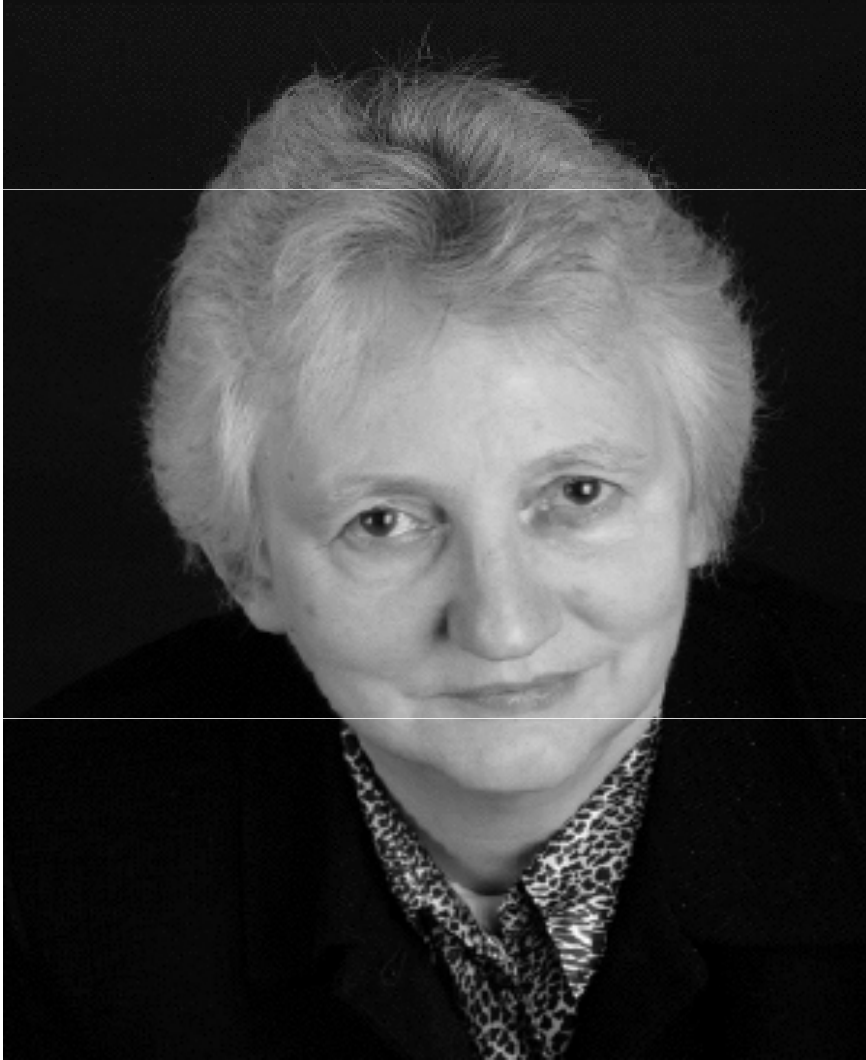Transparency throughout the process of scientific communication

The importance of transparency

"What isn't transparent is assumed to be biased, corrupt, or incompetent until proved otherwise."

"What have they got to hide?"

That's how the world is—like it or not

Why the drive for transparency?

"Every day we read of untrustworthy action by politicians and officials, by hospitals and exam boards, by companies and schools."

"Mistrust and suspicion have spread across all areas of life..."

"We believe that increased accountability will help--and accountability depends in large part on information and transparency"

"The efforts to prevent abuse of trust are gigantic, relentless, and expensive; their results are always less than perfect. Increased transparency is much easier in the age of the internet

It's increasingly difficult to hide anything anyway

Plus people and patients are fed up with being patronised

The doctor patient relationship 1871
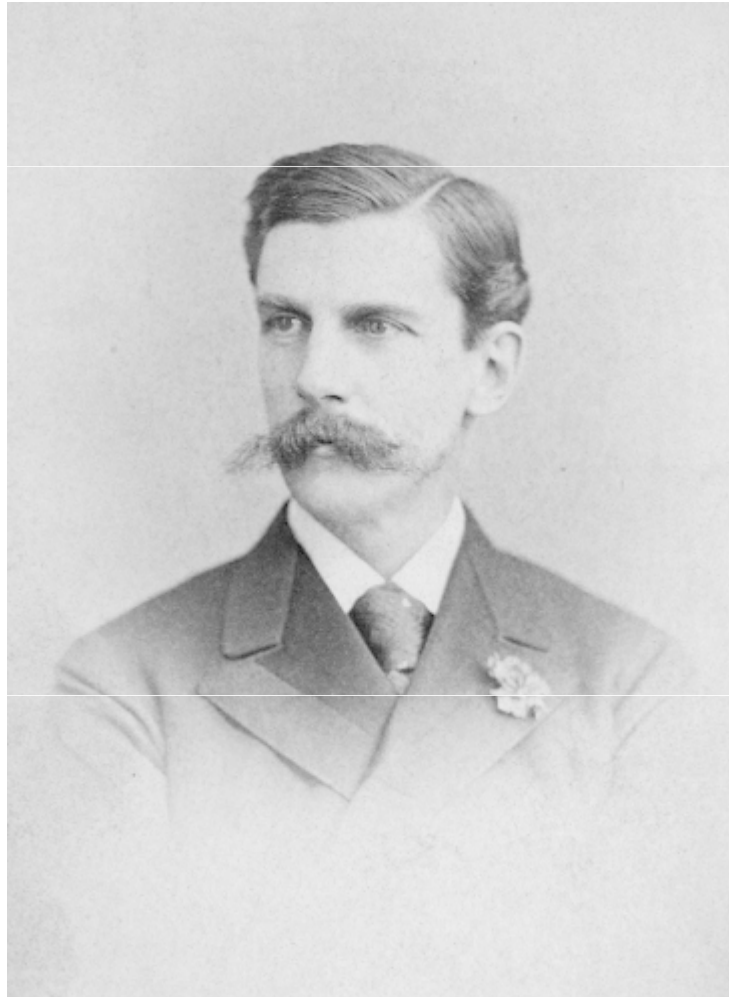
"Your patient has no more right to all the truth you know than he has to all the medicines in your saddlebags...He should get only just so much as is good for him." Oliver Wendell Holmes

Ferguson, 1995

The doctor patient relationship 2007

"The whole structure of medicine has been based on the assumption that physicians have the current information and patients do not. The bottom line is, the consumer will have virtually all the information the professionals have. This is comparable to the way communism fell. Once people start getting in good communication you won't be able to play the game in the same way."Tom Ferguson 2004

Problems in science communication that transparency might solve

Public and professional distrust of science: different story every week, BSE in Britain, MMR

Extravagant claims made on limited data at conferences and in the mass media

Pervasive bias in sponsored research

Research agenda not focused on what matters most

Publication bias

Unfairness in the publication process

Ineffectiveness of peer review

Research misconduct

Inability to access research

Bias in research results

- Review looked at 69 randomised trials of non-steroidal anti-inflammatory drugs
- All of these trials were sponsored by industry
- The drug being investigated (the sponsor's drug) was as good as the comparative treatment in three quarters of the studies and better in a quarter
- In not a single case was the drug being investigated worse than the comparative treatment
- Rochon PA, Gurwitz JH, Simms RW, Fortin PR, Felson DT, Minaker KL, et al. A study of manufacturer supported trials of non-steroidal anti-inflammatory drugs in the treatment of arthritis. Arch Intern Med 1994;154: 157-63.

Companies get the results they want

30 studies compared studies funded by the pharmaceutical industry with results of studies funded from other sources

Five of the studies looked at economic evaluations and in every study the results were favourable to the pharmaceutical company

16 studies looked at clinical trials or meta-analyses, and 13 had outcomes favourable to the companies

Overall studies funded by companies four times more likely to have results favourable to the sponsor than studies funded by others13 of the studies examined the quality of the research
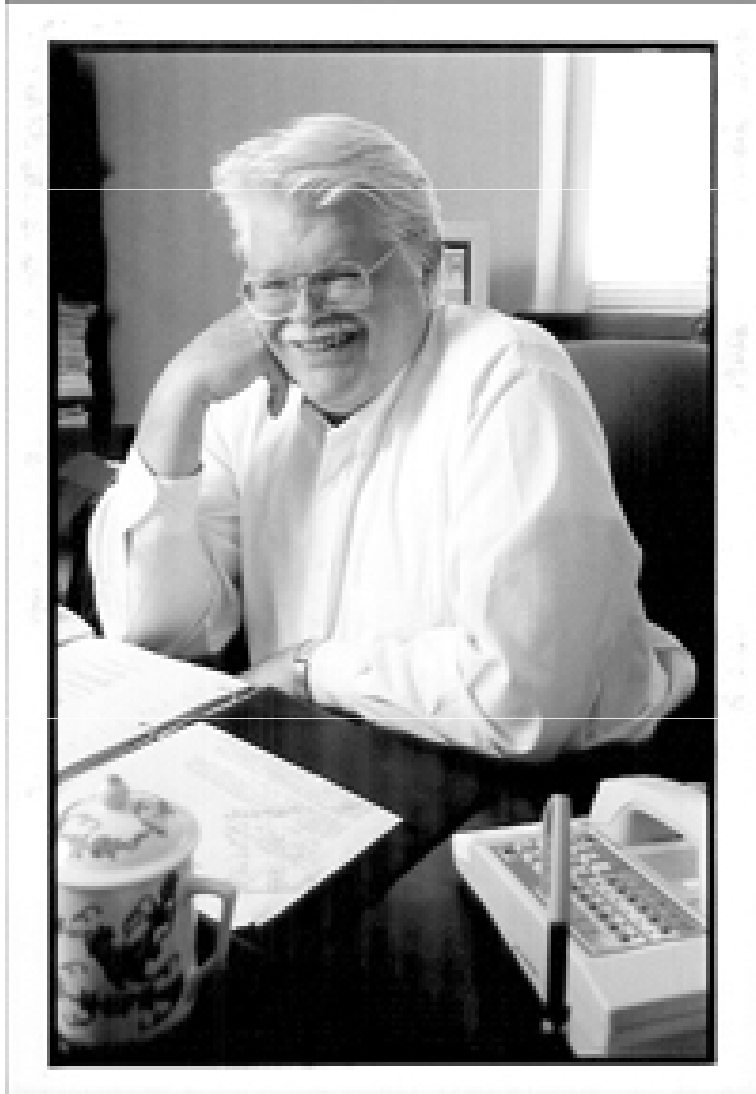
None found the quality of drug company sponsored studies to be inferior

4 found that the research funded by the industry was of superior quality

Wise words

"Disclosure is almost a panacea"

John Bailar

What is the relationship between transparency and trust?

There can be no such thing as complete transparency

"At some point we just have to trust"

As transparency has advanced trust seems to have receded

Increased transparency may lead to increased deception because people may be careful in what they write or say if they know everything is to be made public--using evasions, hypocrisies, and half-truths

They may also resort to spin

"Well placed trust grows out of active inquiry rather than blind acceptance"

People need information they can check and assess its accuracy for themselves

This is demanding

Ingredients of trust in 2007

"If we want to restore trust we need to reduce *deception and lies* rather than *secrecy*"

If you start from a position of trust, then an absence of evidence of being deliberately deceived or misinformed

Accurate, understandable, interpretable, unspun, checkable information

Capacity to understand, interpret, and check the information

Repeated checking of the information without any discovery of *deliberate* deception

Prompt admission of error by the trusted source

Defining transparency

Transparency: the quality of being transparent

Able to be seen through, clear, pellucid; pervious to rays; easily detected, understood; obvious, evident; ingenuous, frank; shining through

The question?

The best research starts with a question

Why not share that question and your method for answering it? With your crowd? (Facebook? A social network for researchers/doctors?) With the whole world?

"Somebody will steal my idea."

"But it's there recorded for all the world to see."

Sharing the question and your method for answering it will refine both the question and your methods

CLOSER EXAMINATION OF THE QUESTION MAY BE VITAL BECAUSE THAT IS HOW DRUG COMPANIES AND OTHERS GET THE ANSWERS THEY WANT

The James Lind Alliance
Tackling treatment uncertainties together

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Welcome to the James Lind Alliance web site

Despite the vast amount of research on the effects of treatments in health care, many uncertainties remain. The James Lind Alliance aims to identify the most important gaps in knowledge about the effects of treatments, and has been established to bring patients and clinicians together in 'Working Partnerships' to identify and prioritise the unanswered questions that they agree are most important. This information will help ensure that those who fund health research are aware of what matters to patients and clinicians.

Research on the effects of treatments often fails to address questions that matter to patients, and to the clinicians to whom they turn for help. The **Database of Uncertainties about the Effects of Treatments (DUETs)** has been established to identify and publish uncertainties reflected in patients' and clinicians' questions about the effects of treatments which cannot be answered by referring to up-to-date systematic reviews of existing research evidence. DUETs is being developed and extended using the infrastructure of the Specialist Libraries of the National Library for Health (**www.library.nhs.uk**), with support from a small team in Oxford co-funded by the Medical Research Council and the Department of Health. DUETs is being used to inform priorities for new research, in particular, those identified through working partnerships of patients and clinicians which have been developed under the aegis of the James Lind Alliance (www.lindalliance.org).

The James Lind Alliance is a non-profit making initiative, being developed under the direction of a broadly-based **Strategy and Development Group**. Its Secretariat is funded by the **Medical Research Council** and the **Department of Health**.

This Web site contains information for those interested in finding out more about the James Lind Alliance, and those who wish to become involved.

Paid Student Placement Scheme

Research priorities in Asthma

Urinary Incontinence - A JLA Working Partnership

The JLA **bibliography** of research reports

Developing a DUETs module

Current Affiliates

The Research Journey

Station	Description	Potential Parties	Notes
1	Define the Condition	Patients, Clinicians, Public, Government	Who is better placed to determine the condition to be researched than Patients and Clinicians?
2	Build a Team	JLA / Patients and Clinicians	Need to be balanced and not tokenistic on any part
3	Ascertain Uncertainties	JLA / Patients and Clinicians	Who better than patient and clinician groups to seek guidance from as wide a membership as possible?
4	Collate Uncertainties and Test	JLA / DUETs	A robust, trusted and independent resource to ensure that "uncertainties" are known uncertainties and not unknown certainties.
5	Schedule Uncertainties and share	JLA / Patients and Clinicians	Independent facilitation at the important sifting stage
6	Prioritise and Fashion Uncertainties	JLA / Patients and Clinicians –	Within an independent and transparent JLA process involving Patients and Clinicians. Uncertainties to be then "fashioned" into ways that appeal / speak to potential funders
7	Funding Commissioned	Patients and Clinicians working with Researchers	Funders to be fully aware of what is a priority for those who are experiencing the effects of uncertainties
8	Design and Manage	Researchers working with Patients and Clinicians	Because Patients and Clinicians have been involved from the early stages they should be committed to the work and also support the Researchers in their quest for funding
9	Undertake Research	Researchers working with Patients and Clinicians	Because Patients and Clinicians have been involved from the early stages it could be expected that Trial recruitment should be easier.
10	Analyse and Interpret	Researchers	Using Patients and Clinicians to determine their important outcomes
11	Disseminate and Feedback	Researchers working with Patients and Clinicians	
12	Implement	Clinicians working with patients.	
13	Monitor and Evaluate	Researchers working with Patients and Clinicians	

Share the protocol

Probably many people do anyway—but not with the world

Routine with Cochrane

Lancet review of protocols, but 12 in 1997, 2 so far in 07—not catching on

Register the trial

Issues around registering trials

Big increase in number of trials since ICMJE required it

But how much information should be given?

Should there be let outs?

"We recognize that requiring public registration of trials whose prespecified goal is to investigate the biology of disease or to direct further research might slow the forces that drive innovation. Therefore, each journal editor will decide on a case-by-case basis about reviewing unregistered trials in this category." ICMJE

"There is no good commercial reason for refusing to register trials." Richard Sykes, former CEO of Glaxo Wellcome

Posting your results, full data set, and software used to manipulate data?

Why not? Should be the default position

Eprint server for physics, maths,computer science, quantitative biology, and statistics since 1996.

300 eprints posted a month for physics; just starting for statistics

Very slow in medicine. Bmj and lancet tried 10 years ago—flopped

Fear of "worrying the public with material that has not been peer reviewed"

But

- Little evidence for the benefit of peer review
- Loads of rubbish published anyway
- Extravagant claims made at conferences without full data
- Claims made directly to mass media without full data

It would be much better if full data and methods were available

The real reason is cultural resistance to change

Cornell University Library

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arXiv.org

Search or Article-id   (Help | Advanced search)

All papers   Go!

Open access to 451,387 e-prints in Physics, Mathematics, Computer Science, Quantitative Biology and Statistics

Subject search and browse: Physics   Search   Form Interface   Catchup

14 Nov 2007: 2007 Holiday schedule. 18 Jul 2007: PDFLaTeX support
See cumulative "What's New" pages.
Robots Beware: indiscriminate automated downloads from this site are *not* permitted.

Physics

- Astrophysics (**astro-ph** new, recent, find)
- Condensed Matter (**cond-mat** new, recent, find)
  includes: Disordered Systems and Neural Networks; Materials Science; Mesoscopic Systems and Quantum Hall Effect; Other; Soft Condensed Matter; Statistical Mechanics; Strongly Correlated Electrons; Superconductivity
- General Relativity and Quantum Cosmology (**gr-qc** new, recent, find)
- High Energy Physics - Experiment (**hep-ex** new, recent, find)
- High Energy Physics - Lattice (**hep-lat** new, recent, find)
- High Energy Physics - Phenomenology (**hep-ph** new, recent, find)
- High Energy Physics - Theory (**hep-th** new, recent, find)
- Mathematical Physics (**math-ph** new, recent, find)
- Nuclear Experiment (**nucl-ex** new, recent, find)
- Nuclear Theory (**nucl-th** new, recent, find)
- Physics (**physics** new, recent, find)
  includes (see detailed description): Accelerator Physics; Atmospheric and Oceanic Physics; Atomic Physics; Atomic and Molecular Clusters; Biological Physics; Chemical Physics; Classical Physics; Computational Physics; Data Analysis, Statistics and Probability; Fluid Dynamics; General Physics; Geophysics; History of Physics; Instrumentation and Detectors; Medical Physics; Optics; Physics Education; Physics and Society; Plasma Physics; Popular Physics; Space Physics
- Quantum Physics (**quant-ph** new, recent, find)

Mathematics

- Mathematics (**math** new, recent, find)
  includes (see detailed description): Algebraic Geometry; Algebraic Topology; Analysis of PDEs; Category Theory; Classical Analysis and ODEs; Combinatorics; Commutative Algebra; Complex Variables; Differential Geometry; Dynamical Systems; Functional Analysis; General Mathematics; General Topology; Geometric Topology; Group Theory; History and Overview; Information Theory; K-Theory and Homology; Logic; Mathematical Physics; Metric Geometry; Number Theory; Numerical Analysis; Operator Algebras; Optimization and Control; Probability; Quantum Algebra; Representation Theory; Rings and Algebras; Spectral Theory; Statistics; Symplectic Geometry

Nonlinear Sciences

- Nonlinear Sciences (**nlin** new, recent, find)

Make all raw data available

Possible in the age of the internet

Guards against fraud (but not completely)

Reviewers can check results

Do data on my blood pressure belong to me? I think so. I want my data to be available to all for public use.

Can make multiple uses of data sets

Why not?

- I collected the data, why should others benefit?
- May be misused

Peer review is a flawed process

- Was unstudied but now extensively studied—very little evidence of benefit, much of problems
- Slow
- Expensive
- Wasteful—studies work their way down the foodchain
- Something of a lottery—concordance only slightly higher than chance
- Doesn't detect errors. Inserted 8 errors into a 600 word paper; around 300 reviewers; nobody spotted more than 5, median number spotted 2; 20% spotted none
- Biased—Peters and Ceci study: 12 papers resubmitted; 3 journal spotted published before; 8 rejected
- Anti-innovatory
- Easily abused—steal ideas, harshly review work of rivals
- "If it was a drug it would never get onto the market." Drummond Rennie
- Central to science, and yet belief in it is based on faith not science

Can peer review be improved?

Blind reviewing—several studies, no overall evidence of improvement in quality of review; blinding fails in around a fifth of stidies

Let authors know the names of the reviewers

Let readers and authors know the names of reviewers on publication

- Reviewers may object initially but will comply

- No evidence of improvement in the quality of the opinion

- Does disclose conflicts of interest

Training reviewers, little evidence of benefit

Let peer review become an open scientific discourse conducted online; the wisdom of many not the few

Returning to the original way of communicating science—as in the 17th century

Declaring conflicts of interest

Of course

Unresolved questions

- Disclose amount of money in financial conflicts?
- Disclosing non-financial conflicts
- When is disclosure not enough?

"Postpublication" comment

"Anything goes" as with many comments on blogs?

Let correspondents be anonymous? (This would be against transparency)

Select comments--with a higher or lower threshold

Publish only selected (? biased) comments

Let respondents comment in the text—a la Wikipedia

Opening up the whole scientific body of research

- Publishers are making money from restricting access to ideas and research
- Why will this restriction be unsustainable?
  - The internet means it can be done
  - Huge benefit from having all research available easily-- appearance of systematic reviews; can be mined
  - Sharing ideas means they increase exponentially
  - Need to publish fast
  - Public paying for research twice
  - Value in the research not the publishing process
  - Publishers ripping off academics
- The question was and still is when will all research be open--not whether

Why doesn't it happen?

- Fear of the unknown
- Academic credit linked to where authors publish
- Devotion to peer review
- Vested interests
  - Commercial publishers will be fine, no need to worry about them
  - Society publishers--outrageous that they should make money from restricting access to research and ideas
  - If you are the British Society for Hypocrisy your mission is to promote hypocrisy, and how can you possibly fulfil that mission by restricting access to the latest research on hypocrisy

Conclusions

Our starting point should be that the every part of the process of scientific communication should be fully open

A case has to be made for closure

I (an extremist?) see no such case

John Milton on "transparency"

"Give me the liberty to know, to utter, and to argue freely according to conscience, above all liberties. Truth was never put to the worse in a free and open encounter ... It is not impossible that she [truth] may have more shapes than one ... If it come to prohibiting, there is not ought more likely to be prohibited than truth itself, whose first appearance to our eyes bleared and dimmed with prejudice and custom is more unsightly and implausible than many errors."

"Where there is much desire to learn there of necessity will be much arguing, much writing, many opinions; for opinion in good men is but knowledge in the making."