

3rd EQUATOR Annual Lecture

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(Post-Workshop preceding the Clinical Trials Methodology Conference 2011)

Bristol Marriott City Centre

2 Lower Castle Street, Old Market · Bristol, BS1 3AD United Kingdom

“Better reporting of better research = better healthcare: a patient view”

Hazel Thornton

I am honoured and delighted to have been asked to give this 3rd EQUATOR lecture and must thank Doug Altman and colleagues for inviting me. I'm constantly astonished at the extraordinary things that happen to me – and receiving that prestigious invitation was indeed a big surprise.

Background introduction – of speaker and topic

Doug has very kindly introduced me to you, and you may even have read my biography on the EQUATOR website, or looked at the accompanying photo, taken back in the 1990s when my hair was brown. I am one, but you are many, but I can make a shrewd guess at the range of expertise you might bring, since you are here for the EQUATOR workshop and the MRC Trials meeting. But your motivations for attending are likely to be varied. What they are will affect the way you listen, both to me and to all the other papers you will hear, and the conversations you will have. To return to my brief biography, it **reports** some facts about me, and the photograph, although a good likeness, does not depict how I look today, but neither **communicates** what has driven me nor **why** I find myself standing here on this platform. It is information clearly stated, but it does not help you **understand** why I'm here.

In this encounter between speaker and audience, you might better understand what I shall try to communicate if you have some idea of **why** I'm pleased to do it, and what my strange route has been from the gullible citizen who obediently and responsibly turned up for her breast screening appointment in Colchester 20 years ago to speaking on a prestigious podium here in Bristol to talk about *‘better reporting of better research’*!

Inadequate information, both in the consultation when I was invited to participate in the UK DCIS Trial for the Management of Screen detected Carcinoma in Situ of the Breast, and, as I subsequently realized, before that when I was invited to attend for breast screening, was one of the initial drivers. But this led me on to believe that the responsibility for seeing that good research led to better healthcare should be a shared one, and to advocate for patient and public involvement in the whole process, and to make attempts to see that ordinary people were educated about these things and be encouraged to see that they could, as citizens, actively contribute.^{1,2} Poor reporting, poor communication, poor understanding of research concepts, and risk, and general statistical illiteracy are all serious barriers and impediments to achieving this aim. The aims and objectives of the EQUATOR Network to work for better reporting are thus crucially

important, so that research reports can provide the very best material for others to use when they communicate along the chain to those people who need to understand as well as they possibly can, what the most up-to-date evidence is in order to make health decisions of one sort or another.

As a tiny example, my biography and photo may be deemed to be `good reporting` perhaps, but something more is needed to jump the gap between reporting, communicating, and understanding – as I am attempting to do now. But if we do not start off with clearly written, factually correct and complete text, text that has also been written with an understanding about what constitutes `good written communication` - particularly of `numbers` - there is little hope of bridging the gap to the communication of research findings to those lay and professional people who will use them to make decisions and take action.

In a moment, I propose to use a recent paper to illustrate that there`s many a slip twixt cup and lip, even if the cup and content are of the highest quality. I refer to the paper published online last month in the *Journal of the Royal Society of Medicine* by Peter Goetzsche and Karsten Jorgensen, entitled *The Breast Screening Programme continues to misinform the public, ignoring repeated criticism and new evidence*.³ The paper is not a report of an RCT, but is a masterly analysis to see whether the recent debate and the new pivotal data about breast screening had had any impact on the contents of the new 2010 leaflet given to women invited for population screening in the NHS,⁴ and on the NHS Breast Screening Programme 2010 Annual Review.⁵ This `story` was taken up by the media with a full page in *The Times* of 1st September 2011⁶, a piece in the *Independent*⁷; in the free London Newspaper *Metro*; and in the *Evening Standard*. It was gratifying to see that *The Times* followed up a day or two later with a 2-page spread looking at large-scale medical screening of various kinds, setting out the pros and cons, asking “*Is medical screening a scientific lifesaver or an unreliable and sometimes dangerous attempt to predict people`s futures?*”

But before looking at that `paper in order to explore some issues, may I offer a few general thoughts?

Introduction

I believe it to be important, as evidently do the EQUATOR Team, to consider things from difference viewpoints, in order to get a better all round picture, to keep things moving on the right track. As with a business with its mandatory Annual Report to the Shareholders, or a Charity organisation`s Annual General Meeting and Reports, it is essential to call people together regularly to take stock, consider what has happened, and to plan future activity and direction against a background of current affairs. Sir Iain Chalmers gave the first EQUATOR lecture in London in June 2008 on the topic of *Achieving transparency in Reporting Health Research* based on his experience and work as a health services researcher. The second was given by *The Lancet* editor, Dr. Richard Horton in September 2009, in Vancouver. He spoke to the title *Re-describing medicine: reporting or reclaiming research for health?* It is now my turn in this third lecture to make a *patient plea* to stimulate and encourage everyone to continue working towards

our common goal of achieving the EQUATOR equation: ***better reporting of better research = better healthcare***. It is set against a background of a fast-moving scenario.

As you are all presumably familiar with CONSORT and other tools provided by the ongoing work of the EQUATOR Network, I propose to stand back a little to paint a much broader picture that looks beyond the medical landscape to the wider world of **citizens**, and the intermediaries who take your reports to use in their communication with Mr. and Mrs Joe Public.

Bridging the gap between information and understanding

The need to bridge the gap between **information access** and **understanding** in health research has been recognised and is being tackled in various ways. Later this month, for example, TalkScience@bl will be hosting a free event at the British Library entitled **Health in the Headlines: Making Sense of the Science?** Who better than Tracey Brown of *Sense about Science* to introduce the subject and stimulate discussion among the audience! That evening, the **Patients Participate? Project**⁸ will also be launching the findings of their 7 month feasibility study on ***how to bridge the gap between Information Access and Understanding in Health Research***. The purpose of the work is to enable patients to understand research better. As they state, having free access to the scientific literature should enable patients to participate in the research process but, in practice, they tend to be overwhelmed by the volume and complexity of the literature. They say, that whilst many medical research charities provide lay summaries, **evidence suggests that academics struggle to describe their work in a way that is accessible to all**. The importance of being able to communicate clearly and effectively in appropriate language cannot be over-emphasised.

As I mentioned, my own sudden invitation to participate in a trial back in 1991⁹, led me to want to see that the public were educated about research. This was one of the main aims of the *Consumers` Advisory Group for Clinical Trials (CAG-CT)* that I co-founded with Professor Michael Baum in 1994.¹⁰ Another opportunity to fulfil this aim was the invitation to be a co-author with Imogen Evans and Iain Chalmers in a book for the general public, first published by the *British Library* in 2006, entitled: ***Testing treatments: better research for better healthcare***.¹¹ In 15 days time, on 18th October 2011, the revised and updated second edition is to be published and launched, thanks to our new publishers, Pinter and Martin.¹²

How does this affect `the consultation`?

Methods of healthcare delivery are undergoing rapid change for a variety of reasons: economic; political; cultural, technological and ideological. Here in the UK, and elsewhere, the central encounter – the consultation – is undergoing a sea-change, as shared decision-making and informed consent come increasingly under the spotlight^{13, 14, 15}. It is to be hoped that more enlightened exchanges and iterations between profession and laypeople will result in better healthcare generally. No longer will patients have to mutely accept what the doctor tells them, but will increasingly question, contribute and take an active part in deciding how their condition is to be managed. To do this, it is essential that, not only are sources of information reliable and of good quality,

but that information is communicated effectively. The pendulum has swung from one extreme to the other since the paternalistic and rather unregulated 1940s to one of shared responsibility with better understanding. It will, I hope, find a more central, sensible and satisfactory place with respect to consent, concordance (rather than `compliance`), regulation, governance and practice. A united sense of purpose is needed, as well as action by those who are aware of the problems, if we are to be able to work to improve the content of dialogues.

I am given hope by two recent important initiatives: the recently published *Salzburg statement on shared decision-making*¹⁶ and the General Medical Council's guidance for doctors, *Good Medical Practice*¹⁷ which is currently being reviewed and is out for consultation. Both call for relationships based on trust and respect, and demonstrate that it is the responsibility of both parties - patients and public, together with health professionals - to responsibly play their part in striving for a better way of working together to test and provide treatments, and to improve public health, as we explain in our book.

The `chain of reporting`

All iterations are fed by reported findings of one sort or another: it must be a `house build on rock, not on sand`, otherwise we all waste our time and healthcare will not `get better`. Knowledge and understanding are built as much by discarding as by accumulating. We have to consider the whole chain of reporting, and particularly that part of the chain that links from the reporting we see in the medical journals to all those people who need to use findings from research in their shared decision-making. They are the doctors and their patients; the people in public health organisations and the citizens they serve; and the politicians and the policy makers and the citizens they are meant to serve.

This means that those medical professionals of one kind and another who write for medical journals must not only have CONSORT and PRISM and so on in mind when they write (as should journal editors and their staff and reviewers when they consider them for publication), **but all of them should never forget the purpose of this work**, and which people it is who need to understand what they have written. It is only a very small minority of the general public who will read the original report of a piece of research in a medical journal, or even a lay summary of that research, but news of it will come to their attention after having gone through intermediaries. Unfortunately, it's not all plain sailing to ensure that a true, sufficiently complete and comprehensible account will reach them and be of use.

Authors of reports of research should remember that they are not just communicating amongst their peers; and they must check their own motivation for doing the work in the first place. Have they lost sight of the ultimate beneficiary – the patient or ordinary citizen? What they have written may be picked up and used, for good or ill, by a range of media journalists: it is essential the account is written bearing that in mind. Press releases will be converted by journalists of varying ability into articles for public consumption; headline editors will use their inventiveness to produce attention-grabbing headlines; other people in the media will provide eye-catching photographs or pictures to illustrate

the `story`. Their purpose is to make it `a good story` that will be the first to hit the news-stands, and be attention-grabbing so that the public will buy.

I can almost hear you thinking, “What I am supposed to do about that?” I believe that, unless we know where our little piece of the jigsaw fits into the whole picture, we might produce a piece that is not as illuminating and well-shaped as it might be, and, furthermore, that responsibility **does** extend beyond `the piece` to `the whole picture`.

Press releases are a case in point.

Philip Wilson, the editor of *BMJ Evidence Centre* recently wrote a BMJ blog about `*The dangers of science by press release`¹⁸. He asked readers to imagine they had just completed a groundbreaking piece of research. He asked if you then (a) go and tell your mates down the pub; (b) publish in a peer reviewed journal; or (c) rush out a press release. He cites the legend that Crick and Watson stylishly chose to stroll into *The Eagle* in Cambridge to announce that they had discovered “the secret of life”. But today it is usually a combination of (b) and (c) - the report in a peer reviewed journal and a rushed out press release. Journals issue press releases about newsworthy studies, giving early access to research on the understanding that no stories are published until after the research has appeared in the journal. This gives time for reporters to prepare their stories and the journals to get their research into the public eye. In this way, everyone benefits.¹² In my view, it is essential that the author of the report and the writer of the press release get together to make sure it is fit for purpose.*

Would that it were as orderly and straightforward as that! But, quite often, tight deadlines; sensationalism; under-resourced or inexperienced journalists; all contribute to the production of misleading and inaccurate news stories. Not to mention easy manipulation of `the facts`, by using relative risks rather than absolute risks, or 5 yr survival figures rather than mortality figures; by selective reporting (`cherry-picking`)¹⁹; and other tricks of the trade. More on that in a moment! Press releases often feature key authority figures from institutions or organisations; this can give the impression in the news story that it is THEY who have produced the findings, rather than it being the product of rigorous scientific method involving well-regulated teams of researchers and others who have produced data which has been clearly and fully reported to the highest CONSORT standards in reliable journals.

I'm sure I don't have to remind you that journalistic style is quite different from formal, medical report writing style. This means that a competent medical report writer or a worthy essayist for a leading medical journal may not have the necessary skill to write a pithy press release, which is why large institutions have their press and media office. What is a press release? One definition I found was that it is a “*pseudo-news story, written in third person that seeks to demonstrate to an editor or reporter the newsworthiness of a particular person, event, service, or product.*” It also informed me that a journalist will be “*looking for a story that will be interesting to his readers and pleasing to his editor.*” Ummm! `Newsworthiness` can get in the way of accuracy. So, too, can cherry-picking of supportive facts¹⁸ and other manipulations of numbers which

are tools of the trade – regrettably used not only by journalists but also by some writers of press releases in Department of Health organisations and other institutions!

An EQUATOR-related anecdote

But, before I give you more thoughts about that part of the chain beyond the report in the journal that I mentioned earlier, to illustrate `shared decision-making` a little further, I should like to tell you **An EQUATOR-related anecdote**, since anecdotal material – if used judiciously - does have its uses, in spite of what purists might say! I must also add that it can also be a terrible scourge.

Aside from the invitation to speak here, another extraordinary EQUATOR-related incident happened to me in July. It happened when I was on an operating table as an NHS patient in Colchester General Hospital having surgery (with local anaesthetic) for basal cell carcinomas on my face. When the surgeon and I were chatting (as you do!), to my astonishment, the plastic surgeon asked me if I knew about CONSORT, telling me that he had had published a survey of output and quality of reporting in randomized clinical trials in plastic surgery!²⁰ Receiving this news as he carried on with his cutting, cauterizing and stitching, cheered me somewhat. Pre-op, in the ward, when he introduced himself to me, I told him that I wanted a good cosmetic result, not necessarily just through vanity, but because I'd got a couple of important lectures to give in October, and didn't want to frighten the delegates. We discussed the various possible surgical options: do a punch biopsy first to be more certain of the diagnosis, followed by surgery (if necessary) two weeks later; with, or without a skin graft; if with a graft, how it might be done – either by a flap, or by using skin from behind the ear; whether to excise one or both lesions at the same time; if without a skin graft, where the line of excision might best be placed. He was surprised when I asked him if he employed the Moh technique, saying that most people don't ask that. The only relevant Cochrane review that I had found beforehand, concluded that the review could not find enough evidence to answer the questions.²¹

Arriving at this part of the shared decision-making had drawn on many considerations: both my surgeon's and my (limited) knowledge and understanding of relevant published reports; the amount and quality of the available evidence; his experience and judgment; my preferences with respect to type and timing of surgery; my personal circumstances; our desire to achieve best cosmetic result; my motivations and hopes for the future and what I might be doing.

But aside from the more formal evidence we use to make decisions about receiving advice and/or treatment from healthcare professionals, or about early detection of disease, or other public health promotions, people cannot help but be affected by a whole host of other influences and inputs that help shape our approach and attitude in these encounters with doctors, drawn from other types of media `reporting` that pervade the society we live in, but all ultimately (one would hope!) going back to the report in the journal. Ben Goldacre described it as `a broader worry`. ***“People make real-world health-risk behaviour decisions based on information from newspapers and if that information is routinely misleading, there are real-world consequences.”***²² ***He also said: “Numbers can kill!”***

In simple terms, the equation `works` when all kinds of good quality reporting ultimately enables a well-informed dialogue to take place between a health professional and a patient or member of the public. But, as we all know, there is inevitably an asymmetry of knowledge and power in those exchanges between health professionals and citizens – be they patients, or citizens who are the focus of public health interventions such as vaccination and screening. And I'm sure I don't even have to mention what topics we might instantly recall in that connection: in many minds, perhaps MMR for the first, where a report in *The Lancet*, no less, led to huge media exposure and general uproar; and breast or prostate screening for the second. And, without my telling you, I'm sure you will recall a string of less-than-adequate (and sometimes conflicting) accounts that appeared in the journals and the popular press.

Some problems are remediable, such as reporting statistics (`numbers`) in ways best understood by `lay` readers; following evidence-based recommendations for good communication; careful choice of words. It took Guy Keleny, writing his *Errors and Omissions* column in the *Independent* last month²³, to draw attention to the absurdity of pompous use of words, citing an April 2010 editorial in the *BMJ* written by a couple of professors from Harvard Medical School and Harvard School of Public Health²⁴: they described `the poor` as `socio-economically disadvantaged sub-groups`!

A topical word about journalists and the media: “the media affects all of us”.

The recent exposure of the scandalous methods that some Murdoch newspaper reporters have used to make their stories more `lively` should lead us to remember, as Ben Goldacre points out, that much popular opinion is shaped by what people learn from the media. And `the media` is full of `health stories` because people today are obsessively interested in such things, and are becoming ever more risk averse, and anxious and fearful as a consequence of this cranked up sensationalism.

Lord Justice Leveson, assisted by six panel members, has been appointed to head the judge-led inquiry into the culture, practices, and ethics of the press.²⁵ It is reported that he said: “*The press provides an essential check on all aspects of public life. That is why any failure within the media affects all of us. At the heart of this inquiry, therefore, may be one simple question: who guards the guardians?*”²⁶ Who indeed? `Public life` is what we citizens make of it; we are all custodians and must all recognise our responsibility to play our part, whoever we are, and whatever our individual rôle. We must not lose sight of the overall, overarching objective. No man is an island.²⁷ We cannot say “it does not concern me”.

The Lancet concurred. An editorial this July entitled *Science journalism: a delicate balancing act*,²⁸ referred to these recent scandals involving media corporations, stating that *the mainstream press still exerts a powerful influence over people's opinions*. A review drew attention to the difficulty of enforcing editorial guidelines enforcing “due impartiality” with respect to programmes put out by the BBC, wondering whether these guidelines were applied too rigidly when it came to science. They stated: “*Programme*

makers must make a distinction between well-established fact and opinion in science coverage and ensure the distinction is clear”.

There can be little doubt that there is general confusion between ‘well established fact and opinion in science’ and between ‘belief and evidence’: it is only too evident in many of the stories in the media that we read today or see on our televisions.

Other kinds of **Anecdote**.

Old as the hills, there is ‘word-of-mouth’: shared anecdotes between friends and family about hospitals; doctors; health experiences; that help shape decisions. Anecdote is so much more interesting and memorable than statistics or government advice! Serious critical appraisal and a rational approach don’t always figure! But for the particular topic in hand, if ‘*better reporting of better research is to lead to better healthcare*’, I think we all have to bear in mind the important links in the chain from reports (of all kinds) available to the medical profession to reports (of all kinds) in the media that go to shape people’s opinions, attitudes, understanding and decision-making. So it is imperative that the basis - the professional report for publication in the medical media is absolutely clear and complete and that both words and numbers are expressed not just correctly (even to correct placing of brackets (parentheses) in formulas!²⁹) but also appropriately, in unambiguous terms, never using a long word where a shorter one will do.

I now want to focus attention on ‘**statistical illiteracy**’³⁰

But first,

What is statistical literacy? This is what Gerd Gigerenzer and colleagues say about it: “*Statistical literacy is a necessary precondition for an educated citizenship in a technological democracy. Understanding risks and asking critical questions can also shape the emotional climate in a society so that hopes and anxieties are no longer as easily manipulated from outside and citizens can develop a better-informed and more relaxed attitude towards their health.*”³¹ They go on to say that statistical literacy in health does not require a degree in statistics. Rather, it means that citizens have basic competencies in understanding health statistics.

Decisions in daily life so often depend on understanding numbers: comparing one set of figures with another; assessing risks and probabilities; reading press reports giving percentages about health matters; reading information leaflets; finding the best mortgage. It is a real-world problem for which most of us have been ill-educated. The German chancellor, Angela Merkel, identified this educational shortcoming, and suggested a remedy. She said³²

“Our society must learn to better assess risks, generally speaking. Living with chance and risk is a big problem. In a world that is becoming increasingly complex, I also think it is important to introduce children at an early age to such issues that will constantly demand their attention in later life.”

There are many ways of setting out numerical facts: in words; using numbers; providing tables; using graphic representations of one kind or another – grids, graphs, pie charts, etc. It follows that it is essential for those attempting to communicate numerical facts

that they know how to do so in the best possible way so that their readers have the best chance of grasping a good understanding. People must be wised up to the potential for manipulation employed by some communicators for bamboozling readers by using less suitable formats. But to be sceptical pre-supposes good understanding. An unaware and statistically illiterate public is easy prey to political and commercial manipulations that can trade on citizens' fears and anxieties – or even deliberately exacerbate them for their own ends.² Unfortunately, many authors of papers and health reports in medical journals and other presentations are unaware that they are not presenting their findings in the best manner: this 'collective statistical illiteracy' involving many players could thus be described as 'concealed' from the very people responsible for setting out the facts, and to society in general, and other involved parties.

What then is **statistical illiteracy**? It is something that

- (a) Is common to patients, physicians, health professionals, and politicians;
- (b) is created by non-transparent framing of information that may be unintentional (i.e. the result of lack of understanding) or intentional (i.e. an effort to manipulate or persuade people); and
- (c) can have serious consequences for health.

When Lisa Schwartz and Steve Woloshin tested physicians' basic numeracy they found that, although physicians were better when compared to the general public, only 72% of the physicians (n = 85) could answer three simple questions about percentages correctly.³³ What can be done about this problem? First of all we have to raise awareness to show that the problem really exists. Gigerenzer and colleagues discuss the importance of teaching statistical thinking and transparent representations in primary and secondary education as well as in medical school. They suggest that this requires familiarising children early on with the concept of probability and teaching statistical literacy as **the art of solving real-world problems** rather than applying formulas to toy problems about coins and dice.

Ike Iheanacho, writing recently in the BMJ,³⁴ suggested we might learn a lesson or two from bookmakers about how to communicate with the public.

Statistics and epidemiology

So, when reporting statistics and risk, research has shown that some ways are better than others.³⁰ Frequencies are generally better understood than percentages or probabilities³⁵; absolute risk should be used rather than relative risk; effects on mortality should be used, not 5- or 10-yr survival data. When people read in the press a reported statement made by an authority figure in the NHS about 5 year survival figures, they are likely to believe what they read, probably without questioning it too much. Take a recent example, comparing the effects on survival of breast screening by mammography of those who have attended for breast screening with those who have not – newspaper readers will gain a very false impression of what breast screening may or may not be able to achieve. People are unlikely to realize or to work out for themselves that lead time will affect the percentages. This is what Nina Lakhani reported in *The Independent* on September 1st 2011, following publication of the Goetzsche and Jorgensen paper in the JRSM that I mentioned:

“Professor Julietta Patnick, director of the NHS Cancer Screening Programme, said: “We know that 97 per cent of women with screen-detected cancers are alive five years later compared to just over 80 per cent of women diagnosed without screening, and screening lowers a woman’s risk of having a mastectomy.”

That statement is not only grossly misleading, but it is also inaccurate: reliable evidence shows that screening does **not** lower a woman’s risk of having a mastectomy³⁶. I’m sure there is no need for me in this company to state the obvious, that the important outcome to look for is effect on **mortality**, but I would ask you to consider what effect that statement has had on ordinary readers. Also importantly, to appreciate what has NOT been stated, and what is ‘hidden’. To be misled about the benefits, and to be denied being told about potential harms, is not a good recipe for achieving equitable healthcare; or effective screening policies; or effective and safe treatments; or – importantly - for upholding and maintaining trustworthiness.

Using relative risk figures is a method used to give a highly inflated impression of efficacy! Politicians and public figures like to mix anecdote and relative risks, and spread ‘misinformation’ in the process. Rudy Giuliani, former mayor of New York, had prostate cancer and used his personal experience to political effect in a 2007 campaign advertisement. “I had prostate cancer 5 or 6 years ago. My chance of surviving prostate cancer in the United States? Eight-two percent. My chance of surviving prostate cancer in England? Only 44 percent under socialized medicine.” That certainly grabbed the headlines – it was also unquestionably wrong. The risk of death from prostate cancer, as Gigerenzer et al point out,³⁷ is actually about the same in American and British men – 26 and 27 prostate cancer deaths per 100,000 respectively.

Giuliani was citing 5-year survival rates. Moreover he was not comparing like with like – there were differences in the people being compared, since American men tend to be diagnosed by PSA screening whereas PSA screening is not nearly so prevalent in Britain, American men tend to be diagnosed earlier. But that does not automatically make them live longer – this is the phenomenon of lead-time bias, which adds to the time spent dying not to the time spent living.³⁸

Today we have scope and power to record and analyse data to a degree unimaginable not so very long ago. But this could be said to be part of the problem as well as an advantage and solution: there is a superabundance of ‘information’.³⁹ As Jack Stilgoe wrote in *The Lancet* when reviewing the new book by James Gleick (of *Chaos* fame), entitled *The Information: a History, a Theory, a Flood*:

Gleick has a rosy view of the human journey from information poverty to the current wealth of information. He sees the major challenge as one of the information overload – finding a useful signal from the noise. But the flood of information creates a whole new set of political questions. What is good

*information and what is dangerous? Is all information equal or does expertise still matter? Who should have access? **Information may be power, but we should not forget that it is not knowledge, and it is not wisdom.***

Conclusion and Question

How then can we bridge the gap between reporting and communicating? What then is my `patient plea`? It is that we don't deny the problems that exist; that we all keep our eye on the main objective of striving to provide better healthcare, whatever it is that we do and whoever we are, since we are all citizens who have a profound interest in ensuring that better reporting of better research **will** lead to better healthcare. We **cannot** fall back on saying that what another person does is no concern of ours. I can do no better than quote the words used by John Donne, the English poet, satirist, lawyer and priest, nearly four hundred years ago:

“No man is an island, intire of it selfe; every man is a peece of the Continent, a part of the maine; if a clod bee washed away by the Sea, Europe is the lesse, as well as if a Promontorie were,as well as if a Mannor of thy friends or of thine owne were;any mans death diminishes me, because I am involved in Mankinde; And therefore never send to know for whom the bell tolls; It tolls for thee....”¹⁹

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¹ Evans I, Thornton H, Chalmers I, Glasziou P. Testing treatments: better research for better healthcare. Second Edition. Pinter and Martin 2011; In press. Publication date 18th October 2011.
http://www.pinterandmartin.com/product/Testing_Treatments_978-1-905177-48-6.

² Thornton H. Essay: “Today`s patient: passive or involved?” *Supplement to The Lancet 2000* (1999) 354:siv48

³ Goetzsche PC, Jorgensen KJ. The Breast Screening Programme continues to misinform the public, ignoring repeated criticism and new evidence. *J R Soc Med 2011; 00: 1-9 10.1258/jrsm.2011.110078*

⁴ Department of Health. NHS Breast Screening Programme leaflet. London: Department of Health, 2010. See <http://www.cancerscreening.nhs.uk/breastscreen/publications/ia-02.html>

⁵ NHS Breast Screening Programme Annual Review 2010.Overcoming barriers. See <http://www.cancerscreening.nhs.uk/breastscreen/publications/nhsbsp-annualreview2010.pdf>

⁶ Smythe, C. Women `misled` over breast screening. *The Times* 1st September 2011. page 3.

⁷ Lakhani Nina. Claims of breast cancer screening success are dishonest, say critics. *The Independent* 1 September 2011.

⁸ Patients Participate! Project
www.jisc.ac.uk/whatwedo/programmes/digitisation/econtent11/patientsparticipate.aspx (accessed 16th September 2011)

⁹ Thornton HM. Breast cancer trials: a patient`s viewpoint *Lancet* 1992;339:44-45

¹⁰ Thornton H. Patients and health professionals working together to improve clinical research: where are we going? *European Journal of Cancer*. 2006; 42:2454-2458, plus Appendix A. online at doi:10.1016/j.ejca.2006.05.022

¹¹ Evans I, Thornton H, Chalmers I. Testing treatments: better research for better healthcare. British Library 2006. Freely available on www.testingtreatments.org in English and six other languages.

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- ¹² Evans I, Thornton H, Chalmers I, Glasziou P. *Testing Treatments: better research for better healthcare*. 2nd edition. London: Pinter & Martin, 2011.
http://www.pinterandmartin.com/product/Testing_Treatments_978-1-905177-48-6.
- ¹³ GMC review to stimulate debate for revisions of *Good Medical Practice* www.gmc-uk.org/gmp2012
- ¹⁴ Emanuel EJ, Menikoff J. Reforming the Regulations Governing Research with Human Subjects. *NEJM*.2011; 10.156/NEJMb1106942
- ¹⁵ Manson NC, O'Neill O. *Rethinking Informed Consent in Bioethics*. Cambridge University Press Cambridge 2007.
- ¹⁶ Salzburg statement on shared decision making. Salzburg Global Seminar: the greatest untapped resource in healthcare? Informing and involving patients in decision about their medical care, 12-17 December 2010. www.salzburgglobal.org/go/477 *BMJ* 2011;342:d1745
- ¹⁷ General Medical Council. *Good Medical Practice* 13th November 2006
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