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for Science and Integrity in Medicine

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IS A CHARITY ALWAYS A GOOD THING?



THE CHARITIES ACT 2011 defines a charity as an organisation established for a charitable purpose. Section 2 of the Act establishes that such a purpose must be for the benefit of the public. It is important to remember the distinction between these two principles, the purpose and the benefit. In section 3 the Act presents a list of purposes that are accepted as charitable, including “the advancement of health or the saving of lives”.

However it is not sufficient for a charity simply to say that this is its purpose; in addition it must be shown that the purpose is beneficial. Public benefit is defined in section 4, where the Act says “it is not to be presumed that a purpose of a particular description is for the public benefit”. Do you detect a bit of healthy scepticism here? What this means is that the claimed benefit must be supported with evidence. For example, although “the furtherance of religion” is a listed purpose, that is not enough on its own. The purpose must be able to demonstrate benefit.

Back in April 2012 I came across some rather odd charities. One was The Maun Homeopathy Project, which operates among AIDS patients in Botswana. As homeopathy has been shown to be devoid of effectiveness, there can be no possibility of benefit to these people. I complained to the Charity Commission, and here is an extract from their response ...

Les Rose is a retired clinical research consultant, and HealthWatch committee member

News

One woman’s screening victory brings hope in Uruguay

ANA ROSENGURTT has won a 4-year legal battle for the right *not* to be subjected to mandatory breast screening. Ana, a 54-year-old computer engineer, lives in Uruguay where working women aged 50-69 are compelled by law to undergo



mammography screening for breast cancer every 2 years. Without it they can’t get a health card that gives them many of their basic human rights – to work, hold a driver’s licence, study at university, and even to join a gym. Screening for breast cancer has questionable benefits and considerable harms.

“The solution is just for me only,” Ana explained. For other women, screening continues to be compulsory. But now Ana will be able to qualify for her health card without having mammograms, though she’ll still have to submit to compulsory PAP smear, blood and urine tests every two years. Uruguay has the highest cancer mortality in Latin

America, and the 10th highest worldwide according to the WHO. Screening has been compulsory since 2006. As far as we know, it’s the only country in the world with such a policy, and Rosengurt is the first woman to have refused. “Because it’s mandatory, people believe that it can’t be bad and, besides, it’s free,” she says.

Brecha, 23 September 2016, <http://brecha.com.uy/la-teta-valiente/>

NHS Wirral CCG ends funding for homeopathy

NHS WIRRAL Clinical Commissioning Group have decided to cease funding for homeopathy after a public consultation concluded that 95% of respondents wanted to stop homeopathy funding immediately, with just 3.7% of respondents favouring a continuation of the service. Now Bristol and London are the only English areas where the therapy is available on the NHS. Michael Marshall, Project Director of the Good Thinking Society and a resident of Merseyside, wholeheartedly supports the decision. Good

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Thinking has just received an Ockham's Award at the sceptical conference QED 2016. They received Best Skeptical Campaign/Event, for their work challenging the provision of homeopathy on the NHS.

The Good Thinking Society, 4 October 2016.

<http://goodthinkingsociety.org/nhs-wirral-ccg-ends-funding-for-homeopathy/>

Peter Gøtzsche receives 2016 HealthWatch Award

PETER GØTZSCHE accepted his award from HealthWatch president Nick Ross with a compelling presentation on "Is it 'controversial' to tell the truth about health care?" The Danish physician, medical researcher and leader of the Nordic Cochrane Centre received the 2016 HealthWatch Award at the 28th HealthWatch Annual General Meeting. Gøtzsche is a fearlessly outspoken defender of integrity in medicine. A report of his talk will appear in the Winter issue of the HealthWatch Newsletter.

Amazon under fire for selling "dubious" health treatments

THE SUN newspaper has attacked online retailer Amazon for selling products claimed to cure autism, HIV and cancer. One 'Tumour Drops' product highlighted by the newspaper investigation reportedly claimed to treat "all tumours, malignant or benign" including breast and stomach cancer. It was removed from Amazon's site after the Sun article was published. However Hulda Clark books such as "The Cure for All Advanced Cancers", which claim that cancer is caused by a parasitical organism, were still available at the time of writing.

The Sun, 6 September 2016,

<https://www.thesun.co.uk/news/1732110/how-web-giant-amazon-endangers-the-sick-and-vulnerable-by-peddling-bogus-miracle-cancer-cures/>

Adaptive pathways: EMA's plan "dangerous"?

THE "ADAPTIVE pathways" proposed by the European Medicines Agency (EMA) aim to shorten the process for bringing drugs onto the market. But independent drug information service Prescrire fears this could lead to a situation in which marketing authorisations are granted on the basis of very limited evaluation. HealthWatch member Alain Braillon, writing in BMJ Rapid Responses, points to the example of the EMA's marketing approval in 2012 of nalmefene for reducing alcohol consumption in patients with alcohol dependence, on the strength of evidence that it reduced alcohol consumption. But two recent systematic reviews, he says, show that evidence that the drug reduces harms in these patients is lacking.

Prescrire Int 2016; 25(174):223,

<http://english.prescrire.org/en/81/168/52124/0/NewsDetail.aspx> and <http://www.bmj.com/content/354/bmj.i4437/rr-0>

UN joins call for clinical trial transparency

THE UNITED Nations has called on governments worldwide to pass legislation requiring clinical trials to be registered, and their methods and results to be fully reported. The Report of the United Nations Secretary-General's High-level Panel on Access to Medicines, released 14 September, explicitly calls for clinical trial study designs, protocols, data sets, and test results to be made publicly available.

AllTrials, 14 September 2016,

<http://www.alltrials.net/news/un-calls-for-global-action-on-clinical-trial-transparency/>

New tool to help people understand health research

A NEW online tool helps you sort the wheat from the chaff of published clinical research. Understanding Health Research is a website that takes you through the process of reading a scientific paper, prompting you helpfully with the questions you should ask yourself along the way, to decide how reliable the information might be. The tool was developed by researchers at the MRC/CSO Social and Public Health Sciences Unit, University of Glasgow, and Sense About Science worked with the team to make it as user-friendly as possible as part of their Ask for Evidence campaign. The tool is at

<http://www.understandinghealthresearch.org/>



Clearing non-science from Oz unis

A CAMPAIGN against unproven therapies in Australian universities is bearing fruit following complaints by Friends of Science in Medicine, our sceptical friends down under. Victoria University website has removed claims that their Osteopathy clinics for babies and children may be helpful in the management of constipation, reflux, and colic in children". The University of New England will no longer offer two courses which had been claimed to provide "qualified health practitioners with clinically orientated education in modern western Herbal Medicine". Friends of Science in Medicine newsletter, 7 October 2016,

<http://www.scienceinmedicine.org.au/images/pdf/newsletter14.pdf>

Sense About Science in the media

SÍLE LANE of Sense About Science gave an inspiring talk to a TEDx meeting in Madrid about the AllTrials campaign. "The hidden side of clinical trials" is available on YouTube at <https://www.youtube.com/watch?v=-RXrGLolGec>. SAS director Tracey Brown wrote in the *Guardian* on 19 September calling out the myth of a 'post-truth society' and talking about the public's interest in evidence. Read at:

<https://www.theguardian.com/science/blog/2016/sep/19/the-idea-post-truth-society-elitist-obnoxious>. On the same theme, the non-profit research organization RAND Europe has published a review: 'Social change and public

engagement with policy and evidence', commissioned by Sense about Science and the Nuffield Foundation, which presents research into how changing conditions influence political engagement, trust, and policymaking. The 60-page report is free to download from http://www.rand.org/pubs/research_reports/RR1750.html

The unicorn in the room

STUDENTS 4 Best Evidence, a blogging network by and for students interested in evidence-based healthcare, continues to pump out stimulating material. In "An invisible unicorn has been grazing in my office for a month... Prove me wrong" Martin Burton, Director of the UK Cochrane Centre, uses an example of an imaginary clinical trial to unpick the difference between absence of evidence and evidence of absence of effect.

<http://www.students4bestevidence.net/invisible-unicorn-grazing-office-month-prove-wrong/>

Alternative therapies

EVIDENCE OF EFFECTIVE THERAPIES FOR DISABLED CHILDREN IS VITAL – AND LACKING



WE BECAME AWARE of HealthWatch from a newspaper article about how some charities may be promoting (or selling) unproven theories or treatments[1]. Another newspaper article from last year highlighted how families with children with neurodevelopmental conditions are a particularly vulnerable group that are susceptible to being exploited and exposed to risks of unproven therapies[2].

PenCRU (the Peninsula Cerebra Research Unit) is a childhood disability research group at the University of Exeter Medical School (www.pencru.org). Core funding from the charity Cerebra enables us to work in close partnership with families with disabled children and clinicians in all aspects of our work. We work in this way to produce, find and share research findings that are accessible, useful and relevant for those who want to use evidence to inform decisions about treatments, therapies and health services ...

Christopher Morris MSc DPhil, Senior Research Fellow in Child Health, University of Exeter Medical School

Visit our website (www.pencru.org), find us on Facebook (Pencru) or follow us on Twitter (@Pen_CRU)

References

1. 'Quack' health groups granted charitable status. Sunday Times, 20 March 2016. www.thesundaytimes.co.uk/sto/news/uk_news/Health/article1680068.ece
2. Autism: how unorthodox treatments can exploit the vulnerable. Guardian, 15 July 2015. www.theguardian.com/science/blog/2015/jul/15/autism-how-unorthodox-treatments-can-exploit-the-vulnerable

Media

WHEN TRUTH IS LOST TO 'BALANCE'

'BALANCE' IS BILLED as the hallmark of good journalism, a fair way of telling both sides of a story, a means of being objective and preventing bias. The BBC Charter and editorial guidelines, for example, emphasise the importance of 'due impartiality'. Balance can work well in straightforward stories: a government minister and their shadow can be given equal time or space to state opposing views; a residents' association can speak out against a radical council plan. But balanced medical and science stories can distort research, generate bogus controversy and result in groundless fear and false hope. They can even contribute to deaths.

Remarkably, 'balance' is rarely discussed in public forums – and when it is, it is not because of scientific considerations. For example, in July last year Cabinet ministers were widely reported as insisting that the BBC "can't be impartial" about terrorists. Chris Grayling, then leader of the Commons, insisted that broadcasters should

not be any more balanced towards Isis than it was towards the Nazis.[1] ...

John Illman, author and journalist, London

John Illman is a former GP editor who spent five years as the *Daily Mail* medical correspondent, eight years as *The Guardian's* health editor and three years as *The*



Observer's medical correspondent. This article is based on an extract from his new book, *Handling the media: communication skills for healthcare* £14.99. Available from <http://www.jicmedia.org/shop/>

BBC refuses to stop using 'Islamic State' to refer to the terrorist group. Daily Mail, 2 July 2015.

<http://www.dailymail.co.uk/news/article-3146855/We-fair-ISIS-BBC-refuses-MPs-demand-stop-using-Islamic-State-refer-terrorist-group.html#ixzz4NLA1tWHj>

References

1. Next you'll be 'impartial' about the Nazis! Cabinet fury as

Meeting report

STUDENT MEETING TAKES US FORWARD

A STUDENT OUTREACH SCOPING MEETING was held on 4th May 2016 at Kings College London, run by HealthWatch Committee members John Kirwan and Debra Bick, to learn about experiences of current healthcare courses and explore different ways in which HealthWatch might be able to reach out to health students who are interested in evidence. The full afternoon programme was designed to facilitate discussion and exploration of possibilities.

The 10 participants included students and senior academics from centres in England and Wales who teach evidence based practice and HealthWatch Committee members. An introductory discussion revealed that evidence is very much on students' minds ...

Professor Debra Bick, Kings College London;

Professor John Kirwan, University of Bristol

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Unless otherwise indicated, all web addresses referenced in this issue were accessed on or after 17 October 2016.

Letters and articles for publication are welcomed and should be sent to the Editor at: newsletter@healthwatch-uk.org For our requirements please see <https://www.healthwatch-uk.org/newsletter/information-for-authors.html>

HealthWatch is the charity that has been promoting science and integrity in medicine since 1991

We stand for:

- The assessment and testing of all medical and nutritional treatments, products and procedures
- Consumer protection in regard to all forms of health care
- The highest standards of education and evidence-based health care by practitioners
- Better understanding by the public and the media of the importance of application of evidence from robust clinical trials

We are against:

- Misleading advertising of health products
- The sale of unproven remedies to the vulnerable and desperate
- Unethical marketing by pharmaceutical companies
- Misconduct in clinical trials
- Media misinformation on health and nutrition
- Government promotion of health and screening programmes unsupported by evidence

Our activities include public debates, awards, a student competition, and this quarterly newsletter. HealthWatch welcomes membership enquiries from those who share its aims. Join at <https://www.healthwatch-uk.org/about/join-healthwatch.html>



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