

A conversation with Tom Kenny on 03/22/13

Participants

- Tom Kenny — Director of External Relations, The NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC)
- Alexander Berger — Senior Research Analyst, GiveWell

Note: This set of notes was compiled by GiveWell and gives an overview of the major points made by Tom Kenny.

Summary

Tom Kenny is the Director of External Relations at the NIHR (National Institute for Health Research) Evaluation, Trials and Studies Coordinating Centre (NETSCC). GiveWell spoke with him as a part of our investigation of ways to improve biomedical research.

The National Institute for Health Research (NIHR) is funded through the Department of Health with a mission to improve the health and wealth of the nation through research. The NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC) is responsible for managing five research funding programmes, known collectively as the NETS programmes.

The discussion centered on the centre's methods for selecting research proposals to fund, and on its policy of requiring the researchers that it funds to:

- Report on their methods in great detail so that other researchers can reproduce their experiments.
- Publish all their findings, independently of whether they're positive, neutral or negative.

About the NIHR

The scope of the NETS programmes' funding

The NETS programmes fund medical research in a large spectrum of clinical areas. The primary clinical research that it funds is mainly Phase 3 and Phase 4 late stage clinical trials, with a smaller amount of funding devoted to Phase 2 clinical trials. NETSCC does not fund lab-based research, other public funders, such as the Medical Research Council (MRC), fund early stage research.

NETSCC's methodology for prioritising research

Research proposals are prioritised based on:

- How important it is to answer the question that the research aims to answer.
- How costly the research will be, and the likelihood of it resulting in an answer to the question.

To do this, NETSCC consults with a panel of experts in the field, including methodologists, statisticians, health economists, patients and clinical experts. This panel assesses the burden associated with the disease being studied, what the most important questions in the field are, and what the most appropriate ways of answering them are.

Adding Value in Research

In 2009, Iain Chalmers and Paul Glasziou published a paper titled *Avoidable waste in the production and reporting of research evidence* in *The Lancet*, (Volume 374, Issue 9683, Pages 86 - 89, 4 July 2009, doi:10.1016/S0140-6736(09)60329-9).

NETSCC has a policy called Adding Value in Research that aims to implement a positive response to the suggestions in Chalmers and Galziou's paper.

NETSCC's policy of contract based funding

NETSCC offers *contract based* funding rather than *grant based* funding. This means that the researchers that it funds are expected to work on the project for which the funding is awarded, independently of whether it yields positive results.

The publication of NETSCC funded research

NETSCC publishes comprehensive reports of the research that it funds in the NIHR Journals Library, a peer-reviewed journal series. It makes a point to publish all findings, not just positive findings, in order to counter publication bias.

NETSCC asks that authors publish their methods in great detail so that others can replicate the experiments. It gives guidelines to authors that specify what should be reported. These guidelines were formulated based on discussion with researchers about what sort of information they need to replicate studies.

Because of the high level of detail required, the publications are monographs that are about ten times as long as usual journal articles.

Data sharing

The NETS programmes are committed to ensuring that the data generated through their funded research is put to maximum use by encouraging data sharing.

Funding of systematic reviews

NETSCC commissions Cochrane Reviews on an annual basis. It also commissions reviews from the National Institute for Health and Care Excellence (NICE) Technology Appraisal Review (TAR) groups and from other review groups.

The Cochrane Reviews sometimes report that there are no high quality randomised controlled trials and don't offer much more information. When this happens, it either means a question has now been answered or it identifies a need for further primary research.

NETSCC sometimes funds combinations of a literature review and a survey of current practice. These fall outside of the standard paradigm for Cochrane Reviews.

NIHR funding of Cochrane's infrastructure

NETSCC manages infrastructure funding for the Cochrane Collaboration, and funds most of the Cochrane review groups (20 total) in the UK. The funding is awarded in 5-year increments.

James Lind Alliance

The James Lind Alliance Priority Setting Partnerships is an initiative that convenes patients and clinicians to identify and prioritise the most important questions in health. Starting in April 2013, NETSCC is going to be actively incorporating the outputs of these partnerships into its own work.

Assorted subjects

Planning fallacy by researchers

It's often the case that clinical researchers underestimate the time that it will take to recruit patients for their studies. The NETSCC contract management and monitoring processes are designed to support researchers and mitigate this risk. There is a process in place to manage contract extensions, should this be required.

A journal for full publication of results in early biomedical research

Tom Kenny believes that an open access journal for full publication of results in early biomedical research would be beneficial. This could counter publication bias towards only positive findings. In order for such a journal to be successful, it would

have to have a high citation rate and associated prestige, which could present a challenge.

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