OPINION: The public should have a major role in deciding funding for large clinical trials

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SEPTEMBER 22, 2014

TAGS: public engagement, research

A dispute between some researchers and the Canadian Institutes of Health Research (CIHR – Canada's largest health research granting agency) about how many large clinical trials should be funded by the CIHR has recently gone public. The scientists believe that more large clinical trials

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The Impetus

- Private and public advocacy by some of Canada's most prominent trialists for more funding for large RCTs by the CIHR
- I am sympathetic, but this would mean expanding the budget of the CIHR, not funding other research or both
- There will inevitably be more high quality ideas than $ - who should decide?

Why are some trails so expensive?

- The intervention costs a lot
- Recruitment of patients is expensive
- The differences being detected are small, which requires large sample sizes (this may be legitimate if the outcome is clinically important and one wants to change practice/policy)

Right now, researchers decide what is important

- Experts in methodology
- Some are clinical or health system experts as well, usually in a specific area of focus
- A tendency of reviewers not to “over rule” the researcher in terms of the importance of a topic outside of their expertise
- In my opinion, this means that RCTs that are ”messy” will score less well than “clean” studies

What if members of the public had a say?

- They are clearly not methodologists (although they could undergo some basic training)
- Importance depends upon the impact of the disease, currently available treatments, whether it is a “neglected” disease, whether the intervention will decrease or exacerbate SES disparities in health, whether the system can afford or accommodate the intervention….
- Rating of the importance of studies has little to do with science, but much to do with values, fairness and legitimacy
- I would suggest that members of the public are as, if not more, appropriate to make this decision (with input from clinicians and policy makers) as researchers

A proposal

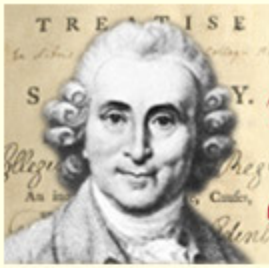
- Researchers focus on scientific excellence; members of the public, clinicians and policy makers focus on importance
- Could approach this two ways: an initial excellence bar or an initial importance bar

Criticisms of this approach

- Science too complicated for the public to understand
- Members of the public have their own biases
- This is a huge burden
- Expensive, and makes an already complicated process more complicated

My bottom line

- Large trials funded from the public purse must be both methodologically strong (there are limitations) and highly important
- The public should have a role in ranking importance
- This may increase their appreciation of the importance of clinical trials
- The James Lind Alliance is doing this for research priorities in specific areas; why not for large RCTs across many areas?



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The Top 10 research priorities were agreed in February 2015 as:

1. Do lifestyle factors (e.g. sleep, stress, diet) influence tumour growth in people with a brain or spinal cord tumour?

2. What is the effect on prognosis of interval scanning to detect tumour recurrence, compared with scanning on symptomatic recurrence, in people with a brain tumour?

3. Does earlier diagnosis improve outcomes, compared to standard diagnosis times, in people with a brain or spinal cord tumour?

4. In second recurrence gliomblastoma, what is the effect of further treatment on survival and quality of life, compared with best supportive care?

5. Does earlier referral to specialist palliative care services at diagnosis improve quality of life and survival in people with a brain or spinal cord tumours?

6. Do molecular sub-typing techniques improve treatment selection, prediction and prognostication in people with a brain or spinal cord tumour?