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The James Lind Alliance: tackling research mismatches

Soon after the James Lind Alliance was launched in 2004,¹ it commissioned a bibliography of how patients, clinicians, and researchers prioritise new research. Arguably slightly subversive, driven in part by a sense that research might not be working harmoniously for the benefit of patients, the results of this study and of subsequent ones found that only nine of 640 papers described clinicians and patients working together.^{2,3} Moreover, substantial mismatches between research activity and questions from patients and clinicians were found. The findings were a shot in the arm for an organisation established to create a research agenda around patients' and clinicians' joint priorities, free of the interests of pure researchers and of the drug industry.

At the heart of the James Lind Alliance, Priority Setting Partnerships (PSPs) unite patients or carers, or both, with clinicians (or representative groups of patients, carers, or clinicians) to prioritise treatment uncertainties for research. Two PSPs have been completed (asthma and urinary incontinence)^{4,5} and eight more are underway, in conditions such as vitiligo or schizophrenia.

An important tool of the James Lind Alliance is the UK Database of Uncertainties about the Effects of

Treatments (UK DUETs),⁶ in which uncertainties (once confirmed as known-unknowns, rather than simply unknown to some patients or clinicians) are gathered, tagged to show whether answering them involves either new research or a systematic review of existing evidence, and then prioritised by the PSP.

A Cochrane Review Group might fast-track prioritised reviews, and UK DUETs has flourished in other ways too. To harvest and to update uncertainties are contractual responsibilities for most of the specialist collections within NHS Evidence, and the editor of UK DUETs is now employed by the National Institute for Health and Clinical Excellence, which hosts NHS Evidence.⁷

UK DUETs' growth shows a heartening commitment to research into treatment uncertainty, and a recent survey by the James Lind Alliance revealed widespread enthusiasm for a priority-setting community of interest. But development of the Alliance's method has not been straightforward and still faces difficulties, such as ensuring that PSP participants stick to the rules—some try to subvert the democratic voting process if they see dearly held priorities being lost—or professional scepticism. Indeed, this scepticism was enshrined in one



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James Lind, 1716–94

researcher’s challenge: why should patients have useful opinions about the directions research should take? And the engagement of clinicians as active participants in some PSPs has been a battle.

Although it took 18 months to complete each of the first two PSPs, both of these and every subsequent PSP have identified hitherto unresearched uncertainties for which new research or systematic reviews of existing evidence could change the care of patients. For example, in asthma, the PSP identified the adverse effects of inhaled steroids as a priority that was formerly insufficiently researched.

Although the patient–clinician involvement model of the James Lind Alliance is new, it joins a growing world of “patient and public involvement” (PPI). Yet even here, a survey commissioned by the Alliance of the extent of PPI in funding decisions of 49 charity supporters of medical research, two UK Department of Health bodies, and one research council,⁸ revealed considerable variation, and little reported evidence of the impact of PPI in funding decisions.

Detailed examples of PPI in charities’ funding decisions are reported in the Association of Medical

Research Charities *Natural Ground* report,⁹ which also makes clear that no one type of PPI fits all. The Alliance’s more specific remit presents a challenge: it needs to be both robust and reproducible while also adaptable to the circumstances of those wanting to use it. A detailed process guide to autonomous PSPs, published in May, 2010, addressed this challenge.¹⁰

Prioritisation has no value if research does not follow, and the James Lind Alliance is collecting information about what happens after PSPs, in parallel with raising funders’ awareness. PSP members can themselves be research-funding charities that use PSP outcomes as a guide, and the UK’s National Institute for Health Research Health Technology Assessment programme works with the Alliance, including “to ensure that any uncertainties identified and prioritised [through PSPs] that may be suitable, are referred to the Programme”.¹¹

An acid test for the Alliance will be to see whether funders used to researcher-knows-best thinking will confidently back priorities identified by a method beyond their comfort zone, and ultimately whether research thus prioritised improves the relevance, effectiveness, and safety of treatments.

More than a decade ago, Iain Chalmers, one of the driving forces behind the Alliance and chair of the UK DUETs Steering Group, cited several examples of the benefits of lay involvement in research. While conceding the need to build the formal evidence-base for the effectiveness of such involvement, he added: “Many people, however, may feel that greater lay involvement in a pattern of research decision-making which has been dominated by professional researchers is justified on the basis of existing informal experience, common sense and justice.”¹²

The Alliance recently sponsored two meetings addressing aspects of common sense and justice. The first meeting, with the Association of Medical Research Charities and National Voices, looked at the extent to which the drug industry heeds the views of patients,¹³ while the second, with the Association and INVOLVE, saw senior commissioners and funders consider how to build on the success of interlinking PPI initiatives.

Future paths for the James Lind Alliance include assessment of whether the PSP method might work for research prioritisation beyond the clinical sphere, and whether brokering of tricky deals between patients and

clinicians can act as a foundation for similar success with the drug industry. The coming years promise to be as exciting as the past ones.

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The potato: fertile ground for more funding

In the good (ie, bad) old days, the highlight of the research month was the arrival in the library of *Index Medicus*, a heavy-weight paperback with lists of new papers and authors since the previous month (for younger online-only readers: a library is a vast and quiet place where books and journals are stored on shelves, and there will be one or more at your institute). *Index Medicus*, published by the National Library of Medicine in the USA, morphed into the internet age in 1997 as Medline. New publications appear daily with an abstract if there is one, and usually with links to the full paper on the publisher's website and with a useful list of related papers.

Medline is for finding published material; it is not a database to be "trawled for evidence". Thence our bête noir: those who search Medline to "prove" some point, usually that their research interest must be very important because more and more is published about it year on year. That is often followed by a vaguely disguised plea of "thus we deserve more funding". What tosh!

We searched Medline with the free-text word HIV between 1996 and 2009, and then for potato in the

same period. The results, though perhaps understandably showing a difference in quantity, reveal a similar trend with the number of publications for both increasing yearly (figure: y-axis for HIV approaches 14 000, that for potato 900). We therefore conclude that the potato, as for HIV, is an increasingly important area for research, and definitely needs more funding. (It doesn't, actually, it just needs eating.)

But such searching is a self-fulfilling prophecy. And what gets our goat even worse is that these Medline-abusers do not even search properly, studiously avoiding Medical Subject Headings (MeSH terms)—no, for them, free-text searching is the order of the day, an error we blithely copied in our searches. Enough is enough, and it is time for an end to this vile practice.

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