



Press Release: Online resource enables patients and clinicians to set the medical research agenda

Embargo: 00.01, May 11th 2010

The James Lind Alliance was established in 2004 to bring patients and clinicians together to agree priorities in treatment uncertainty research. The Alliance's work is based on evidence that a research agenda set in the traditional way - purely by researchers or research funders - can fail to recognise the wishes of those who are ill or those caring for or treating them.

The Alliance today launches its "Guidebook" - an online resource to enable patients, clinicians or the groups that represent them to ensure that research is grounded in what matters to them jointly.

The step-by-step Guidebook sets out how to:

- establish a Priority Setting Partnership
- involve patients and clinicians
- identify treatment uncertainties
- work with the UK Database of Uncertainties about the Effects of Treatments (UK DUETs)
- prioritise treatment uncertainties
- take priorities to research funders

Drawn together from five years experience of patient/clinician partnerships in a range of conditions - from asthma to urinary incontinence, vitiligo to prostate cancer - the Guidebook offers practical advice about and the full protocol for all parts of the priority setting process. It includes templates for questionnaires, terms of reference, draft agendas, and other materials based on case studies of different models of Priority Setting Partnerships. The Guidebook also offers research evidence of why patient and clinician involvement in research priority setting is important, and provides supporting documentation, publications, links and resources.

Lester Firkins, Chair of the James Lind Alliance who became involved in medical research after his son died of vCJD said: "For 35 years I worked in UK banking, and look where not listening to our customers got us? This Guidebook

sets out a tried and tested way in which the medical research world can listen to the patients and clinicians who know best about their ailments. I thoroughly recommend it - not a "Dummy's guide" - more a "Haynes manual."

Sir Iain Chalmers, co-founder of the JLA says: "It is surprising how difficult it is to find out how research funders decide what research to fund. What is clear is that patients, carers and ordinary 'jobbing' clinicians are only very rarely involved in these processes. That is probably one of the reasons that the little evidence there is reveals mismatches between the questions that interest researchers and the questions that interest patients and clinicians. The James Lind Alliance Guidebook will help people who want to try to bridge those gaps."

Encouraging its use, the Guidebook's author Katherine Cowan said "Whether priority setting with patients and clinicians is new or familiar territory for you, the Guidebook is relevant, useful and easy to use."

Notes for editors:

The James Lind Alliance is a not-for-profit initiative funded by the Department of Health and the Medical Research Council. For more information go to www.lindalliance.org or call 01865 517635.

The James Lind Alliance is named after an eighteenth century Scottish naval surgeon and pioneer of clinical trials. Faced with many conflicting ideas and unanswered questions about how to treat the deadly disease scurvy, James Lind confronted this uncertainty by treating his patients within a clinical trial comparing six of the proposed remedies. His trial showed that oranges and lemons were dramatically better than the other supposed treatments.

The guidebook is available at: www.JLAguidebook.org

The UK Database of Uncertainties about the Effects of Treatments (UK DUETs), a key tool of the James Lind Alliance, was established to publish uncertainties about the effects of treatments which cannot currently be answered by referring to reliable, up-to-date systematic reviews of existing research evidence. UK DUETs is housed within NHS Evidence (www.library.nhs.uk/duets)

Sir Iain Chalmers, Lester Firkins and Katherine Cowan are available for interview, as are other members of the JLA and involved patients, charities and clinicians. Please contact Sophie Petit-Zeman as below.

JLA funders:

The **Department of Health** (DH) works to improve the health and well-being of people in England. The Department sets overall policy on all health issues and is responsible for the provision of health services through the National Health Service. See: www.dh.gov.uk

Health and social care research was established in the Department of Health in 1991, since when research programmes and projects have contributed to expanding the evidence base for applied health research and care and to promoting high quality evidence to support health and health-care, policy makers, professionals and the public.

For almost 100 years the **Medical Research Council** has improved the health of people in the UK and around the world by supporting the highest quality science. The MRC invests in world-class scientists. It has produced 29 Nobel Prize winners and sustains a flourishing environment for internationally recognised research. The MRC focuses on making an impact and provides the financial muscle and scientific expertise behind medical breakthroughs, including one of the first antibiotics penicillin, the structure of DNA and the lethal link between smoking and cancer. Today MRC funded scientists tackle research into the major health challenges of the 21st century. www.mrc.ac.uk

Contact:

General media, until May 14th: Dr Sophie Petit-Zeman; s.petit-zeman@amrc.org.uk; 07799764475

Guidebook detail/all enquiries after May 14th: Katherine Cowan; katherine@katherinecowan.net; 020 8691 2232.

ENDS