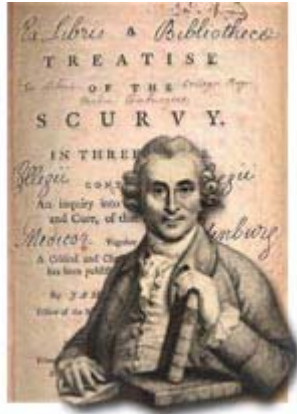




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An Introduction to

THE JAMES LIND ALLIANCE

Tackling treatment uncertainties together

Summary

Despite the vast amount of research on the effects of treatments in health care, many uncertainties remain. The James Lind Alliance has been established to bring patients and clinicians together in 'Working Partnerships' to identify and prioritise the most important unanswered questions. This information will help ensure that those who fund health research are aware of what matters to patients and clinicians.

The James Lind Alliance is a non-profit making initiative, being developed under the direction of a broadly-based Steering Group. Its Secretariat is funded by the Medical Research Council and the Department of Health.

Introduction

Research on the effects of treatments often overlooks the shared interests of patients and clinicians. As a result, questions they both consider important are not addressed. For example when patients, rheumatologists, physiotherapists and general practitioners were asked to identify their priorities for research on the management of osteoarthritis of the knee, there was little enthusiasm for the studies of drugs that the pharmaceutical industry typically supports. Instead, patients and clinicians wanted more rigorous evaluation of the effects of physiotherapy and surgery, and better assessment of the educational and coping strategies that might help patients to manage this chronic, disabling and often painful condition (Tallon et al. Lancet 2000; 355: 2037-40).

The pharmaceutical and medical technology industries and academia play an essential role in developing new treatments. However, the priorities of industry and academics are not necessarily the same as those of patients and clinicians. For this reason many areas of potentially valuable research are neglected.

Furthermore, it should not be assumed that patients and clinicians will always have the same research priorities, unless a process to assess these priorities – like that used for osteoarthritis - has shown that they do. The James Lind Alliance has been established to encourage and facilitate such a process in other areas.

The James Lind Alliance

The James Lind Alliance (JLA) is named after a pioneer of clinical trials, James Lind. Two hundred and fifty years ago, there were many conflicting ideas and unanswered questions about how to treat the deadly disease scurvy. James Lind – a Scottish naval surgeon – decided to confront 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 JLA has been established to help identify and confront uncertainties about the effects of treatments considered important by patients and clinicians. The JLA will promote two principles: first, that addressing uncertainties about the effects of treatments should become accepted as a much more routine part of clinical practice; and second, that patients and clinicians should work together to agree which, among those uncertainties, matter most and thus deserve priority attention.

Specifically, the JLA will facilitate the identification of research priorities **shared** by patients and clinicians, hence its strapline – ‘tackling treatment uncertainties together’. This approach to identifying research priorities remains rare. Most funding bodies consult professionals when they decide which areas of research to support, and sometimes patients and/or the public are involved in the design of particular projects. But few actively seek to establish which areas both professionals and patients agree require further investigation.

The JLA wishes to promote such a joint approach for two reasons. First, identification of uncertainties about the effects of treatments deemed important both by patients and by clinicians is important in its own right, and second, because those who fund and support therapeutic research should take particular notice of these shared priorities.

The James Lind Alliance will:

- **establish a network of affiliate organisations and individuals** who support and wish actively to promote the principles set out above.
- **help to develop a Database of Uncertainties about the Effects of Treatments (DUETs)** containing questions about the effects of treatments being asked by patients and clinicians which cannot currently be answered confidently.
- **foster the evolution of working partnerships of patients and clinicians**, to identify and prioritise their shared uncertainties about the effects of treatments, and then to press for systematic reviews of existing evidence in areas where these are needed, or to influence priorities for additional research.
- **provide a setting as free as possible from major biases** (distorting factors) and competing interests, in which patients and clinicians can meet to identify and promote shared priorities for addressing uncertainties about the effects of treatments.

As used in JLA discourse and documents, **'patients'** includes patients and those (such as carer groups/charitable groups) who advocate for those patients who are unable to do so for themselves; **'clinicians'** implies all health and social service professionals (doctors, nurses, therapists and others who treat patients), not just those who are medically qualified; and **'treatments'** implies all forms of therapeutic intervention for patients, including, for example, drugs, devices, surgical operations, psychological and physical therapies, educational strategies, and the ways treatments are delivered (for example, coordinated care in stroke units).

The evidence from question-answering services for patients and clinicians is that most of their questions are about the effects of treatments. This is why the JLA is focusing on treatments. At this stage in its development, the JLA will **not** attempt to deal with unanswered questions about the frequency, causes and diagnosis of health problems.

Annual meetings of the JLA will provide opportunities to review and evaluate the progress made by the JLA in meeting its objectives.

Operational objectives for 2005

1. To set up a steering group of interested and experienced individuals to guide and appraise the work of the JLA. Members of this group will make a declaration of competing interests.
2. To support and develop a Database of Uncertainties about the Effects of Treatments (DUETs) to underpin and inform the deliberations of JLA Working Partnerships.
3. To foster awareness of the JLA through a programme of communication activities, to encourage organisations and individuals to affiliate to the JLA, and to help to develop Working Partnerships of patients and clinicians.
4. To support and enable the creation of at least two pilot JLA Working Partnerships to identify shared priorities for therapeutic research.
5. Using the experience of the pilot Working Partnerships, to develop, evaluate and describe a workable process that supports and enables JLA Working Partnerships to function effectively; to plan and prepare for JLA meetings, and to agree a shared therapeutic research agenda.
6. By the end of 2005, to have created a platform for widespread publicity to encourage new JLA Working Partnerships.
7. To begin the process of making provision for the continuing development of the JLA, including a three year strategy, starting in 2007.

Influencing objectives

8. To increase the impact of research priorities shared by patients and clinicians on the therapeutic research agenda, and encourage research funding bodies to take account of these shared priorities when funding research.
9. To increase the potential for patients and clinicians to work in partnership throughout the whole process of therapeutic research.
10. To help re-orientate the therapeutic research agenda towards questions and priorities shared by patients and clinicians about the effects of treatments.
11. To promote and demonstrate the value of working partnerships and collaborations between patients and clinicians.
12. To increase public and professional knowledge about therapeutic research.
13. To increase public and professional acknowledgement that recognition of uncertainty about the effects of treatments can be the first step towards improving healthcare.

Affiliation to the James Lind Alliance

Responses to JLA launch documents have made clear that there are many organisations and individuals who identify strongly with the objectives of the JLA, and wish to be involved with and support it. These organisations and individuals are welcome to affiliate to the JLA, and will receive periodic information relevant to progress towards the JLA's objectives.

There is currently no charge for affiliation. Organisations and individuals wishing to become JLA Affiliates should apply to the Secretariat with a brief statement of their background and interests in the JLA, and in particular where they feel they can contribute to the overall objectives of the JLA.

Applicants for Affiliation to the James Lind Alliance should provide the following details:

- *Name and contact details of applicant for James Lind Alliance Affiliation.*
- *A brief statement of background and reasons for interest in the James Lind Alliance.*
- *A brief indication of how you can contribute to the objectives of the James Lind Alliance.*

Applications should be sent by email or post to:

Patricia Atkinson

Administrator, James Lind Alliance Secretariat
Summertown Pavilion
Middle Way
Oxford OX2 7LG

E-mail: patkinson@lindalliance.org

Web: www.lindalliance.org

Governance and Administration of the James Lind Alliance

The JLA is being run and developed by a broadly based steering group, the membership of which is listed below. Further information about steering group members can be obtained from the JLA Secretariat.

Ms Patricia Atkinson	Administrator, James Lind Alliance Secretariat
Sir Iain Chalmers	Editor, James Lind Library
Mrs Sally Crowe (Chair)	Director, Crowe Associates
Professor Glyn Elwyn	Chair, Primary Care, Cardiff University
Mr Mark Fenton	Editor, DUETs
Mr Lester Firkins	Consultant, Medical Research Council
Dr Anthony Harrison	Senior Fellow, King's Fund
Ms Jenny Hirst	Trustee, Insulin Dependent Diabetes Trust
Professor Stephen Holgate	Respiratory Physician, Southampton University
Dr Marcia Kelson	Director, Patient Involvement Unit, NICE
Dr Sandy Oliver	Editor, Cochrane Consumers and Communication Group
Mr Nick Partridge	Chair, INVOLVE
Dr Sophie Petit-Zeman	Director of Public Dialogue, Association of Medical Research Charities
Dr John Scadding	Associate Dean, Royal Society of Medicine
Dr Peter Sneddon	R & D Division, Department of Health
Dr David Tovey	British Medical Journal
Professor Charles Warlow	Neurologist, Edinburgh University
Dr Chris Watkins	Trials Manager, Medical Research Council
Ms Maxine Whitton	Member, Cochrane Skin Group and former Chair, Vitiligo Society