

Executive Summary of a workshop June 2009

“Exploring the unknown: treatment uncertainties in type 1 diabetes”

Context

Research on the effects of treatments often overlooks the shared interests of patients and clinicians, and the questions they both consider important are not addressed. The pharmaceutical and medical technology industries and academia play essential roles in developing new treatments, but their priorities are not necessarily the same as those of patients and clinicians. The James Lind Alliance (JLA) provides support and guidance for organisations who want to work together to identify and prioritise treatment uncertainties. More information can be found at www.lindalliance.org.

‘Treatment uncertainties’ occur when questions about treatment cannot be answered by up to date information based on systematic reviews of reliable research evidence. The JLA interprets ‘treatment’ in its broadest sense, including any intervention that seeks to alter a person’s health status. Potential uncertainties can be collected from a variety of sources, including existing research and literature, and directly via surveys of patients and clinicians.

Uncertainties are verified and then entered into the Database of Uncertainties of the Effects of Treatments (DUETs – www.library.nhs.uk/duets). This forms an important source of information for research funders and commissioners.

If sufficient numbers of organisations want to work together to prioritise these treatment uncertainties then a Priority Setting Partnership is convened. With help from the James Lind Alliance, this Partnership then oversees a process to identify the ten priorities for research which are most important to patients and clinicians. This list is then published and provided to organisations that fund research. So far this process has been completed in Asthma:

http://www.lindalliance.org/Asthma_Working_Partnership.asp and Urinary Incontinence

http://www.lindalliance.org/UI_Working_Partnership.asp

Diabetes

Since the JLA’s inception, people working in diabetes have been interested in how JLA methods could be used to determine research priorities in diabetes. Staff at NHS Evidence Diabetes (<http://www.library.nhs.uk/diabetes/>) have added treatment uncertainties to DUETs.

These have included research recommendations from a variety of sources, and from members of the Insulin Dependent Diabetes Trust (IDDT)

(<http://www.library.nhs.uk/diabetes/Page.aspx?pagename=DUETS>). The database is promoted on

the NHS Evidence Diabetes home page and has been presented at relevant meetings. More recently IDDT, the Juvenile Diabetes Research Foundation, the Diabetes Research Network, and the JLA facilitated an exploratory workshop, with other interested organisations, to explore treatment uncertainties in type 1 diabetes. It was suggested that splitting Diabetes into types 1 and 2 would yield feedback on more specific treatment uncertainty. Invitations were sent to all individuals and organisations who had expressed an interest in the JLA. A range of clinicians, patients, researchers and health information specialists attended the workshop in June 2009.

Treatment uncertainties in type 1?

Workshop participants focussed on key areas of treatment in type 1 diabetes - types of insulin, delivery mechanisms, psychological and social interventions, and blood glucose testing. In the plenary session many other areas of uncertainty were also discussed.

Examples of suggested uncertainties included:

Does the method of insulin delivery (injection vs. pump) have any impact on rates of complications?

Does telemedicine increase the use of blood glucose monitoring in adolescent and young people?

What are the long-term complication rates associated with the various forms of insulin?

Does the Dose Adjustment for Normal Eating (DAFNE) work?

How early, is early to give statins?

How do psychosocial interventions help people with type 1 diabetes cope with life events and challenges to the diabetes lifestyle?

Gathering more uncertainties and beyond

Workshop participants felt that it was important to gather uncertainties from a wide group of clinicians, patients and carers. There was debate about how diabetes research priorities are decided currently, and the need to address commercial interests as part of any priority setting process. Participants agreed to consult their respective organisations to gauge the levels of interest in developing this work further, and to assess the likelihood of resources being made available to pursue it. For the full workshop report and to contact the JLA click the following link: http://www.lindalliance.org/Emerging_Priority_Setting_Partnerships.asp