

Setting research priorities for  
diabetes in the UK:

*how do we agree important topics  
and turn them into fundable proposals  
and high quality studies?*

Simon Heller

University of Sheffield

Chair Clinical Studies Advisory Group

# Clinical Studies Advisory Group

## *Membership*

- Members of the Diabetes Research Network Coordinating Centre
- Researchers, most of whom are clinicians
- Patient/user representatives
  - Susan de Jesus
  - Fiona Kennon
  - Nicky Moxey

# Clinical Studies Advisory Group

## *Remit*

- overseeing the research portfolio
- working with the Department of Health and funders groups to set research strategy
- addressing any gaps in the portfolio
  - by funding new research groups
  - bringing researchers together
  - ?influencing the funders of diabetes research

# Existing research priorities

## Patient self-management

- Understanding why educational interventions provide less and more short lived improvement in metabolic control in the UK compared to other European countries
- To alter behaviour in people who have made 'wrong' choices throughout their life
- To understand reasons for patients' decisions around behaviour change and the essential components of structured educational interventions
- To assess the efficacy of educational programmes to encourage patient self-management for the prevention of the late sequelae of chronic complications,

# User research priorities

*(2008 DRN PPI Conference – Education and support for people affected by diabetes)*

- Starter packs for the newly-diagnosed to combat information overload – make it personalised, less depressing, how to live with diabetes (not how to die from it)
- Better awareness of complications
- Better education programmes for patients – and qualitative research into them to find out what works!
- Education programmes that are cost effective and accessible, and easy to deliver – DAFNE and DESMOND too costly

# Problems in setting research priorities and encouraging high quality studies

- Clear mismatch between approaches of professionals and those with diabetes
- How do we combine the views/priorities of those with diabetes with those of clinicians, those of professionals who conduct the research?

*and ensure that the emerging proposals are developed and funded*

# High quality research studies which have impact (improve treatment and care)

Need:

- Researchers with the necessary expertise, enthusiasm, perseverance in the right fields
- Money from funding organisations who use 'peer review' to judge the quality of the proposals
- People to participate in trials
- Infrastructure to make sure the research happens within the NHS

# James Lind Alliance

## *Remit*

- establish a network of affiliate organisations and individuals
- help to develop a Database of Uncertainties about the Effects of Treatments (DUETs)
- foster the evolution of priority setting partnerships of patients and clinicians, provide a setting as free as possible from major biases

# Purpose of the workshop

- To start bridging the gap between clinician, user and researcher
- To create greater understanding of the challenges in turning ideas into research priorities into fundable research studies
- To choose top 3 topics in chosen area and turn them into research questions