

COMET Newsletter



COMET IV: a unique opportunity to share ideas and progress

On 19th and 20th November 2014, people with an interest in core outcome sets (COS) from around the world came together at The Pontificia Università Lateranense in Rome, Italy, for the fourth meeting of the COMET Initiative. Over 200 participants coming from 14 countries attended the meeting and contributed to making it an international event. COMET IV also featured three workshops, 52 contributed posters (49% increase in posters displayed in 2013 meeting) and four contributed presentations. COMET IV provided a unique opportunity for stakeholders from different environments to share their ideas and progress, and engage in discussion and debate. Participants shared their challenges, needs, solutions and resolutions. The meeting brought together key scientists and consumers responsible for developing and implementing COS, including trialists, systematic reviewers, health service users, clinical teams, journal editors, trial funders, policy makers, trials registries and regulators. There was resounding support for the COMET Initiative and unanimous agreement that COS are valuable and have a vital role to play in the future of clinical trials and health research. The full meeting proceedings (including meeting report and abstracts) will be published in the open access journal *Trials* early this year.



The Pontificia Università Lateranense

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Development of a Dementia Core Outcome Set

The Development of a Dementia Core Outcome Set (COS) study is part of the Neighbourhoods and Dementia Programme, which is funded by the Economic and Social Research Council (ESRC) and the National Institute for Health Research (NIHR). Dr Siobhan Reilly from Lancaster University leads the study, which aims to develop a standard set of outcome measures so that care and treatment received by people with dementia can be assessed and compared across a range of interventions. We are particularly interested in finding out which outcomes are important to people with dementia, carers, healthcare professionals and policy makers. Along with researchers from other universities (Manchester, Stirling, Liverpool and Linköping in Sweden), our research team also intends to involve people with dementia and carers throughout the research process including the development of study protocol, the design of interview questions, and co-facilitating focus groups.

On 10th December 2014, the research team met in Lancaster University to develop the study protocol, in particular discussion was around:

- What do outcome means in the context of dementia?
- The development of the links with other outcome work related to people with dementia;
- Research methods used to generate a list of dementia outcome measures (focus group vs interview);
- Working with member groups to engage people with dementia in the study.

Following this meeting, a final version of the study protocol and application for ethical approval will be submitted in early 2015. For more information about the study, please contact via email at: ldclancaster@lancaster.ac.uk or phone: 01524 592976.



The Neighbourhoods and Dementia Research Study - Development of a Dementia Core Outcome Set (Work Programme 2) Featuring left – right:

Professor Lars-Christer Hydén, Professor Paula Williamson, Dr YingYing Wang, Professor John Keady (Chief Investigator), Dr Caroline Swarbrick and Dr Siobhan Reilly.

Delphi Plain Language summary

A new plain language resource is now available on the COMET website. It is a summary describing the Delphi process. This resource has been developed with the involvement of patients. The resource can be found at: <http://www.comet-initiative.org/resources/PlainLanguageSummary>. You may also find the COMET plain language summary useful – this describes core outcome sets, explaining why they are important and how COMET is working to support the development of core outcome sets. This can also be accessed at the same link as above.

EURO-DIS Webinar

One of the roles of COMET is to raise awareness about core outcome sets and we have been invited to host a webinar for the patient organisation EURO-DIS. EURO-DIS is that voice of rare disease patients in Europe. EURORDIS is a non-governmental patient-driven alliance of patient organisations representing 646 rare disease patient organisations in 60 countries covering over 4000 diseases. The webinar, which takes place in March, will provide an explanation of core outcome sets with some examples of core outcome set studies and will provide a broad overview of the work of the COMET Initiative.

COMET in the news

PGfAR Guidance for Applicants

COMET will be referenced in the PGfAR Guidance for Applicants from February 2015.

COMET V—Registration is now open

The COMET Initiative will hold its fifth meeting in Calgary, Alberta, from the morning of the 20th to lunchtime on the 21st May 2015. Registration is now open.

Confirmed Speakers include:

- Holger Schunemann (McMaster University)
- Mike Clarke (Queen's University Belfast)
- Kay Dickersin (Johns Hopkins Center for Clinical Trials)
- Paula Williamson (University of Liverpool)
- Doug Altman (University of Oxford)
- David Moher (Ottawa Hospital Research Institute)
- John Fletcher (Canadian Medical Association Journal)

To find out more, [click here](#).

To register, [click here](#).

