Development of a new intervention for patients with severe Chronic Fatigue Syndrome/ME: a collaborative approach based on patient and public involvement.

Key impacts
The findings from this project and plans for future work were presented to the All Party Parliamentary Group on ME at Westminster in March 2013 by Clare McDermott (Researcher), Sarah Frossell (Group Facilitator) and Tim Stirgess (Chair of the Dorset ME Support Group).

Ideas on recovery skills and communication generated by the development groups have been used to design a new community based intervention for patients with severe CFS/ME. A feasibility study evaluating this intervention is currently being conducted in Dorset and Oxford. This study is funded by the National Institute of Health Research and peer reviewed by the National School of Primary Care Research. Results from this study are expected in 2016.

Insights on communication skills generated by the development work have been used to design a training programme for specialist CFS/ME health professionals, titled ‘Recovery focussed communication for CFS/ME’. The group facilitator, Sarah Frossell, delivered this training to the Dorset CFS/ME Service team in 2009 at their request. The training has been evaluated by a research team involving independent researchers from the University of Southampton, The University of Cumbria and Bournemouth University. This study, which used an action research approach, has been submitted for peer reviewed publication. Training has also been provided to health professionals from the Oxfordshire CFS/ME Service and the Dorset CFS/ME Service for Children and Young People.

Members of the development groups have also contributed to the design of a national scoping exercise on service provision for patients who are severely affected by CFS/ME. This study has been recently accepted for publication by BMJ Open.

Collaborations
This development project is supported by the Dorset ME Support Group and has involved over 40 individuals with CFS/ME and carers in Dorset and Hampshire.

Outputs
The action research study on ‘Recovery focussed communication in CFS/ME’ was presented as a short oral presentation at the annual conference for College of Occupational Therapy (Glasgow, 2012), and as a poster presentation at the National Conference for the British Association of CFS/ME (Milton Keynes, 2012). Full paper currently submitted for publication.


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This poster summarises independent research funded by the National Institute for Health Research School for Primary Care Research (NIHR SPCR) The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.