What is C-CHANGE?

C-CHANGE is a five-year research project to develop and validate a patient-centred case-mix classification for adult palliative care. This will reliably reflect the complex needs and concerns of patients and families to enable the delivery of better quality care in the last year of life and more efficient use of resources. This project, led by Dr Fliss Murtagh, Professor Irene Higginson and the research team at the Cicely Saunders Institute, King’s College London will:

- Define and measure complexity
- Measure outcomes in relation to complexity
- Develop and validate a patient-centred case-mix classification
- Test different models of palliative care in terms of both effectiveness and cost-effectiveness

C-CHANGE at the EAPC

The C-CHANGE team attended the EAPC conference in Copenhagen this May and presented two posters; “Discovering the hidden benefits of cognitive interviewing in two languages: the first phase of a validation study of the Integrated Palliative care Outcome Scale (IPOS)” and “Using Electronic Tablets to Collect Outcome Data in Palliative Care - Help or Hindrance?”. These posters, which have been created by both the OACC and C-CHANGE teams, reflect some of the research which took place during Workstream 1 of the C-CHANGE project, in which the IPOS outcome measurement tool was validated and different ways of collecting patient data were explored. More information about these posters can be found on the next page of this newsletter.

The EAPC World Congress is a bi-annual event, which brings together clinicians, researchers and educators in the field of palliative care. Over the duration of the Congress, there are plenary talks from experts in the field, free communication sessions, and parallel sessions, as well as a poster exhibition where the work of delegates can be showcased. More information about the congress can be found on the EAPC website (http://www.eapc-2015.org/).

EAPC 2016
9 -11 June, Dublin

The next EAPC World Research Congress will be held at University College Dublin between 9th-11th June 2016. Abstract submission will open in early summer and close 15th October 2015.

IPOS validation study: Progress Report

IPOS is a brief measure designed to capture the main symptoms and concerns of patients receiving palliative care.

The IPOS validation study is now nearing completion. Phase one of the IPOS validation consisted of cognitive interviewing specifically focusing on increasing the face and content validity of IPOS.

We collected 32 cognitive interviews with patients and staff, resulting in further refinement of IPOS. We have submitted our first paper on the patient cognitive interviews conducted in the UK and Germany and we presented a poster at the EAPC in Copenhagen with the results.

Phase two of the IPOS validation involves psychometric testing; we have now completed data collection at 8 sites across the UK and are very pleased to have recruited 250 patients and 137 staff into the study.

Psychometric analysis is currently underway looking in detail at the construct validity, reliability and responsiveness of the IPOS and we are looking forward to publishing these exciting results shortly.

The growing team, from left to right: Katie Witcombe (C-CHANGE Administrator), Dr Fliss Murtagh (Principal Investigator), Cathryn Pinto (Research Assistant), Dr Mevhibe Hocaoglu (Research Assistant), Dr Ping Guo (Project Manager), Dr Mendwas Dzingina (Research Assistant in Health Economics), Sophie Pask (Research Assistant), Alice Brown (Research Assistant)
Recent Publications

IPOS Validation Phase 1

Collecting Outcome Data Using Electronic Tablets

Why did you decide to become a member of/join the PPI group for the C-Change project?

Well, it’s because it deals with palliative care and end-of-life care and seems to allow for considering a spectrum of issues from palliative to end-of-life. This portrays my own experience of going through the terminal stages of my late husband, who went through many terminal points at different phases of his illness. You could see the system is trying to get things done to make patients comfortable but there could be some improvements. Some of the resources that should have been there were not used. So I decided to join this study because I believe we should provide resources in an efficient and cost-effective way. And I have some suggestions about this that I would like to see implemented.

How has your experience as a PPI member for this study been so far? Was there anything you particularly liked?

The project is very open and the members I’ve met so far are very receptive. I feel as if I could thrive along with this project or get them to take certain things on board. I think it is very important to look at things from the point of the consumer. And that is why we should have more groups like this.


PPI Profile: Victoria Nnatuanya

Victoria is one of the Patient and Public Involvement (PPI) representatives who meet regularly with the C-CHANGE team to help with the development of the project. If you would like to learn more about PPI involvement, please visit http://ow.ly/MnmP7

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Further information available at: www.csi.kcl.ac.uk/c-change

The views and opinions expressed by authors in this newsletter are those of the authors and do not necessarily reflect those of the NHS, the NIHR, MRC, CCF, NETSCC, the NIHR Programme Grants for Applied Research programme or the Department of Health.