

**Reinhard Guss**

Consultant Clinical Psychologist, Kent and Medway NHS Trust  
Chair, Faculty of the Psychology of Older People (FPOP), Co-Chair, Dementia Action Alliance

**Agnes Houston MBE**

Member of FPOP consultation, European Dementia Working Group, SDWG

# Working with people with Dementia in the production of Professional Guidance Papers: The FPOP Early Stage Dementia Papers



The British  
Psychological Society  
Promoting excellence in psychology



Division of  
Clinical Psychology  
Faculty of the Psychology  
of Older People

**April 2016: Alzheimer's Disease International, Budapest**



The Dementia Engagement  
and Empowerment Project



# Overview of presentation

- **The FPOP Papers on Early Stages of Dementia**
  - Summary of aims and envisaged contents
- **The DEEP Network**
  - linking local groups in a national network
- **The East Kent Forget Me Nots**
  - Example of a local/regional involvement group aiming at wider influence
- **FPOP, DEEP, Forget Me Nots**
  - a national consultation on professional guidance documents



The British  
Psychological Society  
Promoting excellence in psychology



Division of  
Clinical Psychology  
Faculty of the Psychology  
of Older People



Division of  
Clinical Psychology

Faculty of the Psychology  
of Older People



The British  
Psychological Society

Promoting excellence in psychology

## FPOP: Purpose of the Faculty

The Faculty for Psychology of Older People exists to deliver the vision of the British Psychological Society (BPS) which is:

“To promote excellence and ethical practice in the science, education, research and practical applications of psychology.”

FPOP website:

It works to encourage the exchange of information, ideas and expertise about psychological approaches with older people.



## FPOP Dementia Workstream from July 2012

### Aims:

- Professional practice guidance on early stages of dementia (published free at [www.bps.org.uk/fpop](http://www.bps.org.uk/fpop))
  - Dementia Action Alliance (BPS signed membership)
  - MSNAP (FPOP partner organisation of RCPsych)
  - Influencing National policy development
  - Engaging with Alzheimer's Societies and other 3<sup>rd</sup> sector
  - Raising dementia awareness within BPS systems
- 2013 Board of Trustees' thematic priority on Health and Well-being, with a specific focus on dementia

# BPS Dementia Advisory Group



The British  
Psychological Society  
Promoting excellence in psychology

## Constitution - 2015

A reference group to support Society activities in relation to the Board of Trustees' thematic priority on Health and Well-being, with a specific focus on dementia

Operates under the aegis of the Society's Professional Practice Board and Research Board

## Aims

To set out a clear statement of the Society's position on issues relevant to dementia

To provide evidence-based briefings for the Society's Policy Advisers to assist them in responding to consultations and emerging issues, and to inform the work of the Society

To enable clear statements about the distinctive contribution of psychologists in relation to dementia

**Draft and consultation completed, publication early 2016** [www.bps.org.uk](http://www.bps.org.uk)

# FPOP Papers on Early Stages of Dementia

- Aim to provide psychologically informed response to Policy drive towards earlier diagnosis and higher diagnosis rates
- Initially to address:
  - Pre-diagnosis counselling and consent
  - Neuropsychological assessment
  - Communicating about dementia
  - Post-diagnosis psychosocial support and interventions



# FPOP Papers on Early Stages of Dementia

- Brought together clinical and academic expertise from across the Faculty in an Expert Reference Group and forming smaller writing groups
- Aim to involve people living with dementia throughout the process of writing
- Quotes and feedback shared with writing groups, informing development of successive drafts



The British  
Psychological Society  
Promoting excellence in psychology



Division of  
Clinical Psychology  
Faculty of the Psychology  
of Older People

# Quotes from people living in with dementia from consultation

- The sooner you use the word [dementia] the better. If a medical person avoids using the word, it puts it way up there
- “...they shouldn't be focused on what pills to give us; they should be focused on feelings! They should ask, ‘Are you coping?’”
- There is a lot going on that I just don't know about...Why isn't something being done to bring it all together and raise people's awareness of what is out there?”



From 12 to 70+ groups = more than 500 dementia voices

- Groups are all shapes and sizes

- Local and national influence

- People with dementia as contributors, participants and citizens

- Developing a national dementia movement - people with dementia shaping agendas



The Dementia Engagement and Empowerment Project



The Dementia Engagement and Empowerment Project

# FPOP/DEEP Consultation

## Involving People Living with Dementia

- Working with Dementia Engagement and Empowerment Project (DEEP) to consult with people living with dementia through Dementia Action Alliance (DAA) since Jan 2013
- Two joint pilot workshops on early/timely diagnosis and psychosocial interventions (July, August 2013)
- Document by people with dementia (Sept 2013) identifies:
  - Importance of early diagnosis
  - Need for comprehensive psychosocial aftercare
  - Lack of information on psychological and psychosocial interventions – need for a “catalogue” of psychosocial interventions



The British  
Psychological Society  
Promoting excellence in psychology



The Dementia Engagement  
and Empowerment Project



Division of  
Clinical Psychology  
Faculty of the Psychology  
of Older People

# Initial consultation group

- Framework tested with Forget Me Nots in a day workshop
- Discussion groups organised into the FPOP work stream papers' subjects - people chose which discussion group to enter based on interest
- Questions used as prompts to facilitate 4 small group discussions
- Discussion grounded in people's experiences - discussion outcomes shared with the larger group
- Afternoon discussion focused on format, usability and accessibility of the catalogue of psychosocial interventions
- Change of focus to a tangible document that could be touched and used



# FPOP/DEEP consultation

## Workshops with people with dementia

- ✦ Initial one day workshop with Forget Me Nots (April, 2014)
- ✦ Shorter discussion groups with DEEP groups - Scottish Dementia Working group, EDUCATE and Friends Together, Redditch (May and June, 2014)



The British  
Psychological Society  
Promoting excellence in psychology



The Dementia Engagement  
and Empowerment Project



Division of  
Clinical Psychology  
Faculty of the Psychology  
of Older People

# Agnes Houston



# Impact of FPOP/DEEP Consultation:

- Changes to the programme of writing and content
- Gathering the main psychological and psychosocial interventions evidenced and recommended in early/moderate dementia: the “*Guide to Psychosocial Interventions*”
  - Accessible language and structure
  - What is it? How does it work? Who can offer it? What are the benefits/possible down sides? What is the evidence? Who recommends it?
- *Position Paper* summarising Service User’s views and recommendations
- *Quotes* from people with dementia illustrating professional papers
- *Accessible version* of the “professional” document due early 2016



The British  
Psychological Society  
Promoting excellence in psychology



The Dementia Engagement  
and Empowerment Project



Division of  
Clinical Psychology  
Faculty of the Psychology  
of Older People