



The Dementia Engagement
and Empowerment Project



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Clinical Psychology

Faculty of the Psychology
of Older People

Reinhard Guss

Faculty of the Psychology of Older People (FPOP)

Rachael Litherland

Dementia Engagement and Empowerment Project (DEEP)

The national service user consultation on BPS/FPOP guidance on early dementia care

DAA Dementia
Action Alliance

Alzheimer's
Society

Leading the
fight against
dementia

UK Dementia Congress, November 2014



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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**
 - a local/regional involvement group aiming at wider influence
- **FPOP and DEEP**
 - a national consultation on professional guidance documents



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FPOP Papers on Early Stages of Dementia

- Aim to provide psychologically informed response to Policy drive towards earlier diagnosis
- 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



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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?”



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



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- 42 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



National work of DEEP network

- **Influencing House of Lords Select Committee - on review of Mental Capacity Act**
- **Reviewing National Dementia Strategy**
- **Contributing to British Psychological Society's work on best practice approaches to diagnosis of dementia + post diagnosis support**
- **Standing group of DEEP members at national Dementia Action Alliance meetings**
- **Creating dementia friendly conferences and meetings**

Good practice guidance from DEEP

DEEP Guide



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Collecting the views of people with dementia

Key messages

- Organisations and services increasingly want to engage with people with dementia to find out their views.
- People with dementia across the UK are committed to improving services by giving their views. However, this must be organised in a supportive and respectful way.
- Organisations and services should be clear about the ways in which they will involve people with dementia in their work.

Why do organisations need the views of people with dementia?

People with dementia are users of local services. They are in a unique position to share what it is like to live with dementia. Through involving people with dementia, organisations can ensure they are providing appropriate support and services.

People with dementia also have a right to a say about dementia policy, services and support.

Which organisations need the views of people with dementia?

All organisations, services and businesses that come into contact with people with dementia may be interested to know their views, eg:

- A local NHS memory service wanting to know the best way to run its clinics.

DEEP Guide



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Tips for organisations wanting to consult people with dementia about written documents

Key messages

- Many organisations produce documents that may affect the lives of people with dementia.
- Organisations can improve their documents if people with dementia share their views.
- Many people with dementia can take part in consultations on written documents but they may need support to do so.
- People with dementia have the right to have input into strategies, policies and procedures that affect them.

Why consult people with dementia

'Nothing about us without us!' This saying reflects the fact that people have a right to a say in decisions that affect their lives.

People with dementia and their carers often have unique insight into an issue and valuable knowledge and experience.

Consulting with people with dementia will add credibility to your work, especially, but not only, if the document is about dementia.

Working with groups or individuals?

Some people with dementia are able and willing to work in a group, while others prefer to work one-to-one or alone, perhaps with the support of a carer.

East Kent Forget Me Nots: the Beginnings

- June 2011: KMPT Dementia Service User Envoy
- July 2012: inception of a psychology supported active service user involvement group for people with a dementia diagnosis, based on systemic principles
- Nov 2012: inaugural meeting of East Kent FMNs with 5 members
- Sept 2013: first cohort of undergraduate Psychology student supporters
- Nov 2013: 12 Members, review of first year achievements
- April 2014: West Kent group founded
- Sept 2014: second cohort of Psychology student supporters refined procedure for joining, maintaining and leaving
- Oct 2014: 21 Members



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East Kent Forget Me Nots: Systems of Support

- Part of the trust's Patient Involvement Programme
- Annual review meetings with senior trust staff
- Funding of meeting space and travel
- Dedicated time from two senior Clin Psychols
- Joint chairing with Dementia Service User Envoy
- Joint review and planning meetings
- “Year out” Psychology student supporters
- Small number of identified members per supporter
- Regular Clinical supervision for supporters
- Part of DEEP Network



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East Kent Forget Me Nots: Memory Service Work

- Interview panels for staff appointments
- Speakers at Post-diagnostic courses
- Reviewing and writing trust information leaflets
- Commenting on cluster care pathway design
- Speaking at MAS information events
- Presenting to GPs, CCGs and Commissioners
- Consultation to Health, Social Care and Third Sector
- Wider involvement, conferences, national organisations
- MSNAP reviewer training



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Participants of Consultation: the Kent Forget-Me-Nots

Carolina Young & Chris Norris

- Experience of FPOP Consultation
- Hopes for participation



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FPOP/DEEP Consultation

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



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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)



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FPOP/DEEP

National Consultation Groups

- Shorter and more flexible process
- Categories combined based on outcomes from Forget Me Nots discussions
- Small and large group discussions
- Differences between people with dementia who could directly share and recollect the timeline and impact of diagnosis and those who could not but focused on psychosocial support to live well with dementia



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Impact of FPOP/DEEP Consultation:

- Changes to the programme of writing and content: the Guide to Psychosocial Interventions
- Gathering the main psychological and psychosocial interventions evidenced and recommended in early/moderate dementia
 - 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?
- Position Paper summarising Service User's views and recommendations
- Quotes from people with dementia illustrating professional papers



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