SCIENCE AND USER ENGAGEMENT – A CASE STUDY

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Third FLARE Summer School, San Lorenzo Del Escorial, Madrid, Spain, 7 September
The Pressure for User Engagement

The New Dynamics of Ageing Programme

Engaging Users in the NDA

The Special Case of Older People’s Involvement

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THE PRESSURE FOR USER ENGAGEMENT

- Top Down: from governments and research councils emphasising **impact**
- Bottom Up: from a wide range of organisations (business, NGOs) emphasising **knowledge exchange**
- Bottom Up: from older people emphasising **democracy** and **human rights**
- Largely reactive change in research culture resulting in a continuum of practices from tokenism to integration
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The NDA is a multidisciplinary research collaboration to both investigate the new dynamics of ageing and the various influences shaping them; and to show how their consequences can be managed to achieve the maximum benefits for older people and society.

- ESRC, EPSRC, BBSRC, MRC, AHRC
- Budget = £22 million
- 2005 – 2012
- 35 projects, 136 senior researchers, 35 post docs, 24 PhD students
- 128 others e.g. Advisory, partners, admin teams

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Anthropology/Ethnography
Art History/Visual Art
Art Therapy
Biology/Genetics
Biomechanics/Bioengineering
Biomedicine/Bio-gerontology
Business Studies/Management
Chemistry
Computer Science
Cultural Studies
Demography
Design
Development Studies
Ecology
Economics
Education
Endocrinology
Engineering
English
Epidemiology
Ergonomics
Geography
Health Sciences/Primary Care
Information Studies

Mathematics
Media Studies
Medicine
Museology
Music
Neuroscience
Nursing
Nutrition
Physics
Physiology
Physiotherapy
Planning
Psychology
Social Gerontology
Social History
Social Policy
Social Work/Social Care
Sociology
Sports Sciences
Statistics
Theatre Studies/Drama
Transport Studies
Law/Socio-legal Studies

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THE NEW DYNAMICS OF AGEING RESEARCH PROGRAMME

PROGRAMME OBJECTIVES

- Generate new knowledge: life course influences, changes and increasing diversity in meaning and experience of ageing
- To encourage and support the development of new multi- and interdisciplinary perspectives on ageing
- To encourage comparative research and provide new opportunities for UK science to link with other countries
- To support a new generation of multidisciplinary researchers
- To provide a sound evidence base for policy, practice and product development so that research contributes to well-being and quality of life

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1. Ageing Well Across the Life course
   i) Active Ageing
   ii) Autonomy and Independence
   iii) Later Life Transitions
   iv) The Oldest Old

2. Ageing and its Environments
   i) Resources for Ageing
   ii) Locality, Place and Participation
   iii) The Built and Technological Environments
   iv) The Global Dynamics of Ageing

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USER ENGAGEMENT IN THE NDA PROGRAMME

Commissioning:
• Highest quality science, multi-disciplinarity and user engagement
• Commissioning panel and peer review

Supporting:
• Specific project funding
• Preparatory networks innovation
• Follow-on funding
• Programme meetings
• Programme and project advisory groups
• User workshops, findings
• Programme partnerships

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The Sus-IT research community

User organisations

Older people

Academic Expertise in Sus-IT

Participation processes
Participative design
Interactive theatre
Change management
Inclusive/user-centred design

Panels, groups and individuals

Panel of 1000 elders
Voluntary Action Charnwood
Mintoes
U3A, etc.

Consultants, Advisors & Steering Group

Representatives of older people (advocacy; policy making)

Help the Aged
Age Concern, etc.

Cognitive psychology
Gerontology
Demography and ageing
Social informatics
3D environments
Assistive technology
Digital media accessibility
Interactive design

Microsoft
Ambient Performance
Dolphin
AbilityNet
London Borough of Barnet
Local Government East Midlands
Charnwood Borough Council
ROL
NIACE
OATS

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THE SPECIAL CASE OF OLDER PEOPLE’S INVOLVEMENT

- Consumerism (Tokenism) vs. Empowerment
- A Matter of Human Rights
- Essential for Beneficial Research Outputs
- Support for the New Politics of Ageing
- Pressure from Funding Agencies

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Aims

- To advise the Director on the overall shape, structure and balance of the programme from the perspective of older people.
- To help to monitor outputs from the programme and consider their implications for older people.
- To help to disseminate the outputs from the programme, especially to older people, and to encourage discussion of the findings.
- To act as a resource to the programme on issues concerning the involvement of older people in all stages of the research process.
- To give advice where requested to individual research projects within the programme.

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THE NDA OLDER PEOPLE’S REFERENCE GROUP

Assessment (interim)

- Continuum of Involvement
  - Active participation (steering group, testing instruments)
  - Passive communication (emails, telephone)
  - None

- What works?
  - Integration of OPRG members into project
  - OPRG acting as translators of academic research
  - Getting feedback from OPRG
    - research design
    - instruments
    - contacting older people

- Benefits for projects and Programme

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Key Challenges

- Early involvement of OPRG
- Clear guidelines
- Budget
- Difficulties in communication
- Time and staff resources
- Skills matching to project needs
- Question of representation
- Fit with different disciplines
- Ethics

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Indicators of Likely Success

- Openness on Both Sides (2-way learning)
- Programme Capacity
  - Meeting of OPRG (compare notes, solidarity)
  - Joint meetings
  - Funding and flexibility
- Non-exploitative
- OPRG Representative as Research Team Member
- Regular Information Flow

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Role Potential

- Early input to engagement plan
- Help with project communication
- Training resource
- Input to future research proposals
- Networking resource
- Help with knowledge transfer
- Ambassadorial

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Example of Helpful Input to Research

The OPRG made a number of recommendations for changes to first phase developments of WP2’s inclusive research tools. However, the OPRG also strongly advised that the research tools be completely re-evaluated to also include a wider age range of research participants. The OPRG commented that the focus on the barriers in the built environment – namely the provision of public lavatories – if focused just on the over 50’s, may continue to stigmatise the facilities and the older people who rely on them, but that opening the research to all ages would offer a more balanced and inclusive solution that would cater to all members of the public throughout the life course.
Recommendations

- Policy of strengthening user involvement in ageing research
- Responsiveness to user priorities
- Capacity building
- Coordination of European ageing research
- Dedicated funding
- A ‘user engagement’ requirement
- A paradigm of user methodology
- Support for NGOs
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MUCHAS GRACIAS
THANK YOU

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