SOCIAL
CARE
WORKFORCE
RESEARCH
UNIT

WISE OWLS REVISITED: INVOLVING OLDER PEOPLE IN RESEARCH ON AGEING

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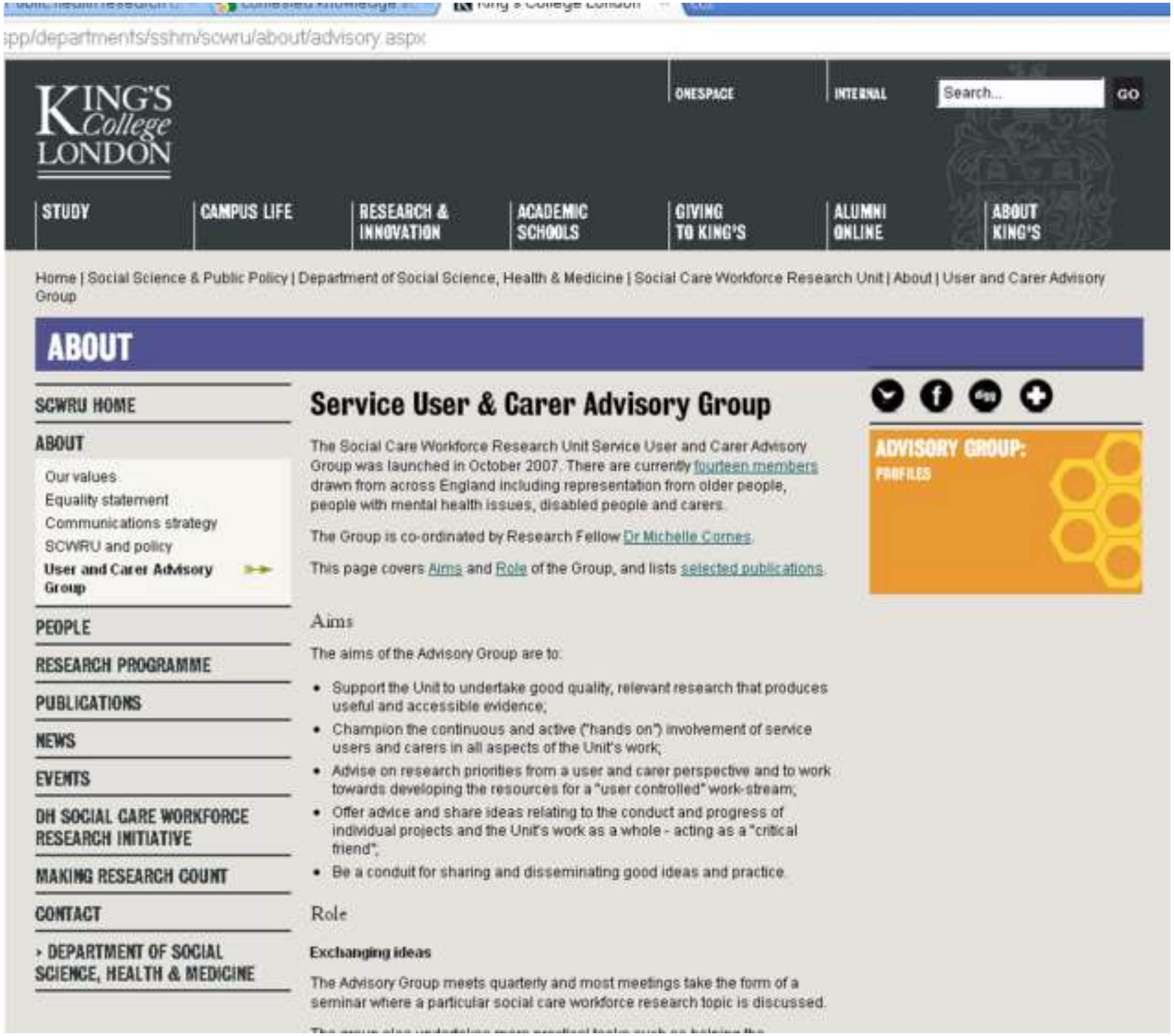
KING'S
College
LONDON

Wise owls

- Thinking and reflecting on older people's engagement in research
- Examples amid generalities
- Wise owls – discussion of involvement of older researchers co-op in NSF for Older People evaluation

Standing group



Service User & Carer Advisory Group

The Social Care Workforce Research Unit Service User and Carer Advisory Group was launched in October 2007. There are currently fourteen members drawn from across England including representation from older people, people with mental health issues, disabled people and carers.

The Group is co-ordinated by Research Fellow Dr Michelle Cornes.

This page covers Aims and Role of the Group, and lists selected publications.

Aims

The aims of the Advisory Group are to:

- Support the Unit to undertake good quality, relevant research that produces useful and accessible evidence;
- Champion the continuous and active ("hands on") involvement of service users and carers in all aspects of the Unit's work;
- Advise on research priorities from a user and carer perspective and to work towards developing the resources for a "user controlled" work-stream;
- Offer advice and share ideas relating to the conduct and progress of individual projects and the Unit's work as a whole - acting as a "critical friend";
- Be a conduit for sharing and disseminating good ideas and practice.

Role

Exchanging ideas

The Advisory Group meets quarterly and most meetings take the form of a seminar where a particular social care workforce research topic is discussed.

Costs – money, admin. and energy

scie
social care
institute for excellence

At a glance 50

October 2011

Reimbursements and payments for service user involvement

Key messages

- Service user involvement refers to service users and carers participating in consultations and events.
- Barriers to involvement have been eased for service users and carers who are in receipt of state benefits.
- Service users and carers who are paid for involvement may be reimbursed out-of-pocket expenses without affecting their benefits.
- Service users and carers who are involved may now decline an offer of a payment, ask to be paid a lower amount, or ask for the payment to be made to a charity, without 'notional earnings' being applied.
- Changes to expenses and notional earnings only apply where the paid involvement is required by law.
- Service users who are in receipt of certain incapacity related benefits may now earn up to £97.50 a week for up to a year at a time or for longer. Neither their incapacity related benefits or housing benefits are affected providing they follow benefit procedures.

Introduction

This At a glance briefing looks at benefit changes that can make it easier for service users and carers to get involved in paid participation for social care consultations and events.

When service users and carers are in receipt of state benefits they must keep to benefit rules. These rules were originally designed for people who wished to undertake some part-time work. Some of the rules were found to be inappropriate for involvement as it differs from part-time work in many ways.

Organisations have faced considerable difficulties in ensuring that service users and carers who get involved in social care events do not have their benefit entitlement adversely affected. Complex systems were required for administrating offers of payment and covering expenses.

The Social Care Institute for Excellence (SCIE) in partnership with Care Quality Commission (CQC), Skills for Care (SfC), General Social Care Council (GSCC), Office for Disability Issues (ODI), Carers UK and Shaping Our Lives worked with the Department for Work and Pensions (DWP) to make changes to the regulations which govern the treatment of expenses and application of notional earnings. Changes were secured through legislation in 2009.

'Organisations have faced considerable difficulties in ensuring that service users and carers do not have their benefit entitlement adversely affected.'

- Important to clarify
- Esp when moving from expenses to fees
- Univ requirements
- All encompassing to pay per activity?
- How to manage problems?
- Co-investigator roles

Our experiences of a standing group

Refresh and renew – managing withdrawal, inducting the new.

Managing the practicalities.

More than the meetings; specific invitations to events, lectures, seminars.

Differentiating Public from Patient/Service User/Carer Involvement.

Offering opportunities for co-research.

Ensuring that all staff know what is happening, who is involved, how to make the most of this resource; not just a few.

Research realities

- Systematic or scoping reviews (hard)
- Dataset analysis (hard)
- Comments on interview schedules, approaches to recruitment, publicity
- Appointment of staff
- Emerging findings
- Continuity on advisory groups

A recent systematic review

- Commissioned to include qualitative interviews to supplement literature findings
- Tendency to find them more interesting and quotable
- Comparison of depth of analysis of literature versus interviews

Experts by experience

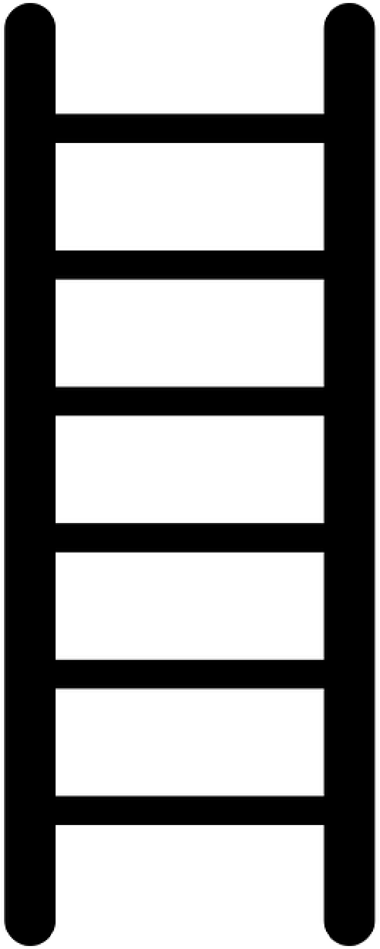
- Suits some subjects
- Risk of being too vague
- Outlier experiences
- Can be very valuable but can be hard to manage
- Proxy views
- Skills of facilitators and meeting chairs

An example

- Study of disease diagnosis
- Lay members of advisory group – hard to keep engaged – meetings infrequent – gaps widened if missed
- Illness and carer commitments; rich qualitative data

The ladder

- Arnstein’s ladder helpful and amazingly long-lasting
- Maybe too linear
- Makes sense in discussions

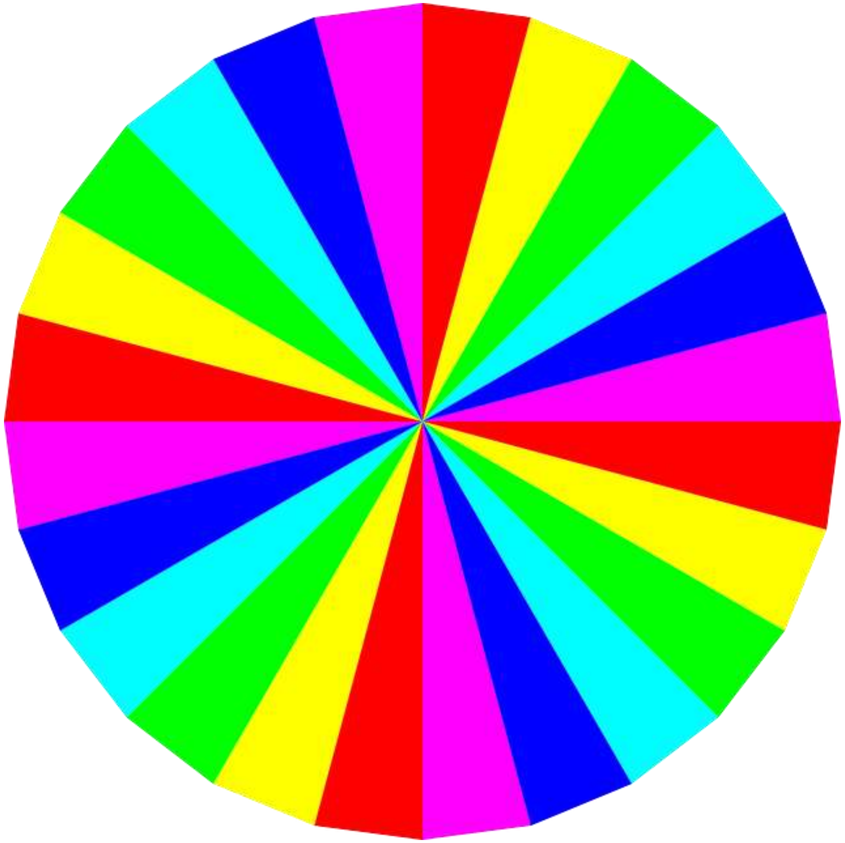


Concluding remarks for us in BSG

- Multiple routes - eg standing group – and/or project groups if necessary (some including wider stakeholders)
- Continuity – terms of reference emphasising ‘critical friends’ & ambassadors
- One point of contact (but admin support)
- Demonstrating impact (eg in reports, website, lengthy minutes of meetings) – Ensure visibility especially in write-ups
- Personal or representative?
- Diversity: at many levels

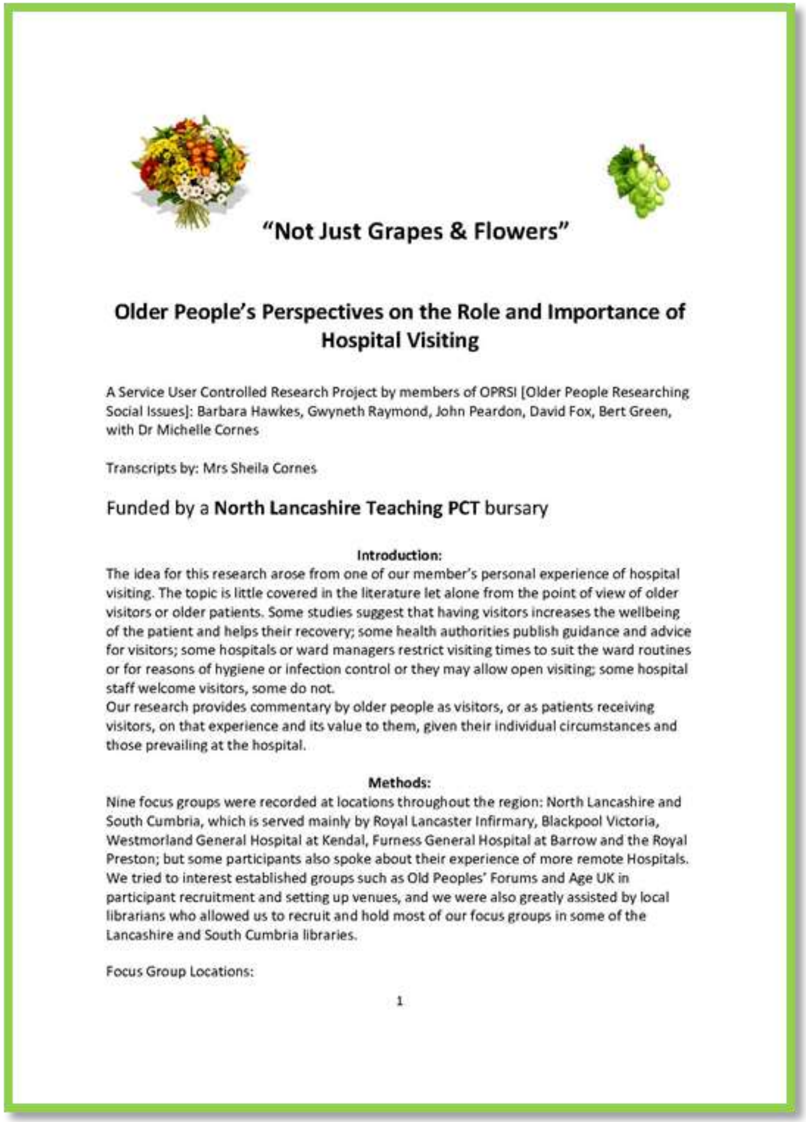
Funder imperatives

- Increasing – can range from User/ PPI network scores to Decision making Panel membership as peers
- Some variations of expectations – e.g. advisory group membership to co-investigators or research network mentors



Co-production

- Emancipatory
- Elements of user control
- Recognises people as assets; promotes reciprocity; values work differently; builds social networks (NEF, 2013).
- Roles and expectations



"Not Just Grapes & Flowers"

Older People's Perspectives on the Role and Importance of Hospital Visiting

A Service User Controlled Research Project by members of OPRSI [Older People Researching Social Issues]: Barbara Hawkes, Gwyneth Raymond, John Peardon, David Fox, Bert Green, with Dr Michelle Cornes

Transcripts by: Mrs Sheila Cornes

Funded by a **North Lancashire Teaching PCT** bursary

Introduction:

The idea for this research arose from one of our member's personal experience of hospital visiting. The topic is little covered in the literature let alone from the point of view of older visitors or older patients. Some studies suggest that having visitors increases the wellbeing of the patient and helps their recovery; some health authorities publish guidance and advice for visitors; some hospitals or ward managers restrict visiting times to suit the ward routines or for reasons of hygiene or infection control or they may allow open visiting; some hospital staff welcome visitors, some do not.

Our research provides commentary by older people as visitors, or as patients receiving visitors, on that experience and its value to them, given their individual circumstances and those prevailing at the hospital.

Methods:

Nine focus groups were recorded at locations throughout the region: North Lancashire and South Cumbria, which is served mainly by Royal Lancaster Infirmary, Blackpool Victoria, Westmorland General Hospital at Kendal, Furness General Hospital at Barrow and the Royal Preston; but some participants also spoke about their experience of more remote Hospitals. We tried to interest established groups such as Old Peoples' Forums and Age UK in participant recruitment and setting up venues, and we were also greatly assisted by local librarians who allowed us to recruit and hold most of our focus groups in some of the Lancashire and South Cumbria libraries.

Focus Group Locations:

Patient and public involvement (PPI): common justifications – widely applicable

- ethical benefits
- improvements in research design
- help with recruitment
- assist synthesis of data
- advance user knowledge, rights and interests

Challenges

- Only the fit and few
- Able and articulate
- Activists’ own agendas
- Mirror the researchers so lack of challenge
- How to manage inequalities
- Involving early – acknowledging delays or no starts

Benefits of hindsight

- More scope to address involvement in job recruitment, job descriptions, appraisal & promotion criteria
- Specialist roles possible if large funding or other investment or pass activity to third sector
- Curious lack of overlap with professional training user groups and research advisory groups
- Skills can be learned and practiced