

EVALUATING EXPERT BY EXPERIENCE INVOLVEMENT IN RESEARCH CAPACITY BUILDING INITIATIVES

Insights from the Kent Research Partnership



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DISCLAIMER

This project is funded by the NIHR Health and Social Care Delivery Research (HSDR) Programme (NIHR131373).

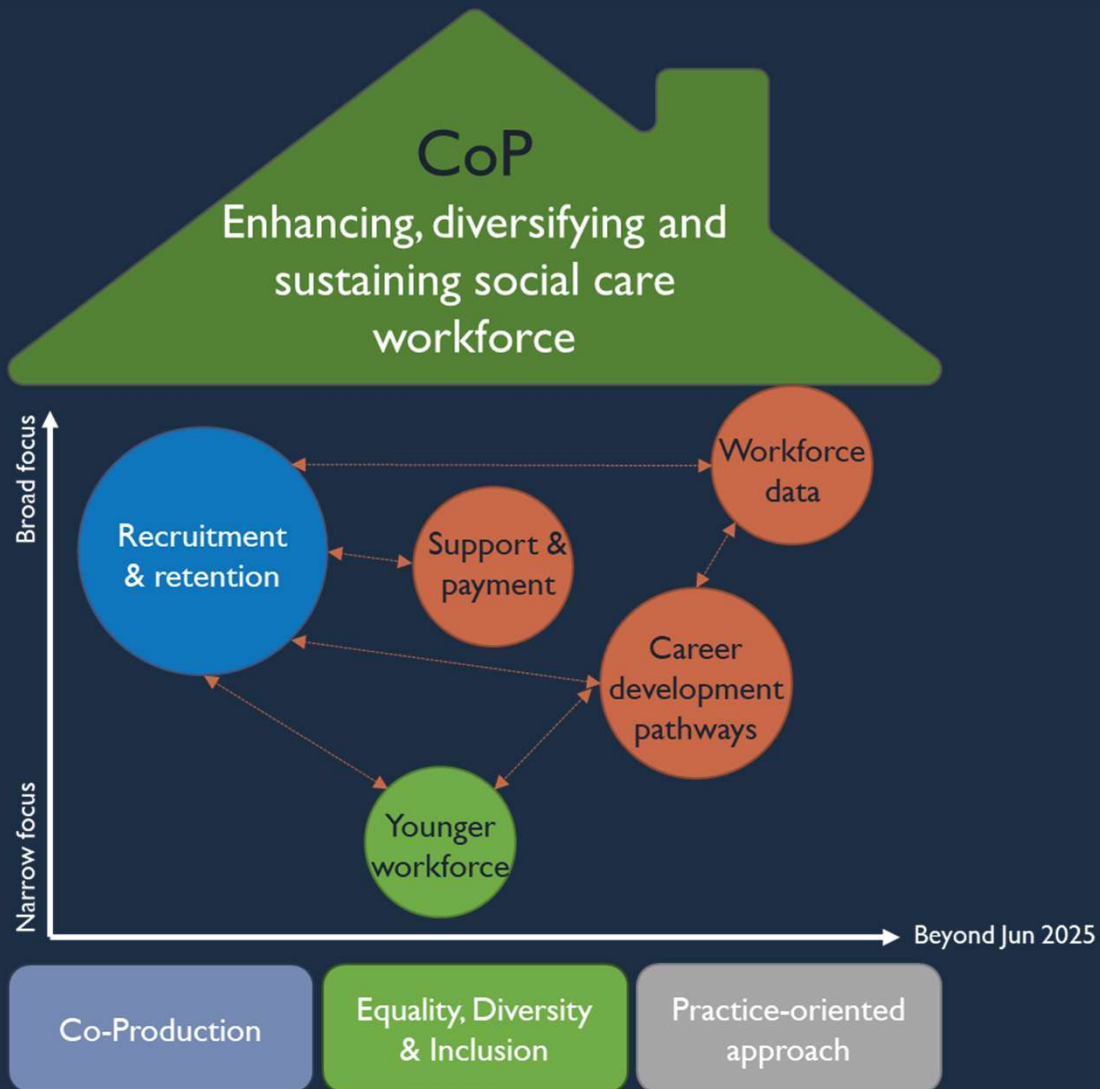
The views expressed are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.



Kent Research Partnership

Building research capacity
in adult social care

Two Communities of Practice



- Supporting people with complex conditions throughout the lifespan
- Enhancing, diversifying and sustaining social care workforce



Dr Wenjing Zhang
Research Fellow &
Qualified Social Worker



Dr Vanessa Abrahamson
Research Fellow &
Occupational Therapist



Lilly Trapp
Research Facilitator

Get in touch with us on
KentResearchPartnership@kent.ac.uk

Researchers in Residence

Cross-sector networking opportunities



Priority-setting for Adult Social Care research in Kent



'Research-Informed Practice' Events



RiR role involves



Support for 'Communities of Practice' and Fellowships

Improving access to research resources



Research clinics and training



Practitioner Fellowships



Thriving, surviving or not at all coping: factors affecting burnout in Social Workers

Hannah Kingsford
Social Worker, KCC



Exploring barriers and enablers that influence working-age individuals with MS in considering employment

Sophie Fournel
CEO of Disability Assist



Supporting neurodiversity within social work: A qualitative study investigating social work manager roles.

Lisa Richey
Social Worker, KCC



Research training only, with an aim to learn about evaluation of digital interventions in their service

Bethany Preston
Care Worker, Tender Loving Carers

3



Stakeholder Events to
Set Local Priorities

51



'Communities of
Practice' Meetings

4



Media
Appearances

24



Lived Experience
Group Meetings

3



Awards Received

13



Video-Recorded
Training Sessions

4



Practitioner
Fellowships Funded

65



Talks & Conference
Presentations

£5m



Further
Funding

Key Achievements

of the Kent Research Partnership



24



Lived Experience Group Meetings

Meet the Kent Research Partnership's Lived Experience Working Group

The Lived Experience Working Group is an integral part of the Kent Research Partnership. Our group members attend the two Communities of Practice meetings to provide our insights and reflections, and we also regularly present about our own experiences and ideas to an audience which includes people working in the sector, academics, policymakers, and others. We support the Research and Training Fellowship applicants and fellows as lay advisors and contribute to training and events. We are learning about co-production in research through training and experience and are helping to measure 'what works' by contributing to the evaluation of the partnership as a whole. We are working to develop our research skills and confidence so that we can offer support, advice and challenge throughout the life of the partnership (and beyond!) to support the project's overall aim of building a research culture in adult social care.

Meet our members and the range of experience we bring to the Working Group:

HELLO my name is
Lyn

When I retired from being a primary school headteacher, I wanted to get involved with voluntary work in my community so joined the Local Involvement Network – now Healthwatch (since 2014). I have several long-term conditions and I can offer my lived experience of these to different health and social care arenas.

Key areas of interest: building relationships with providers and commissioners and bringing the patient voice and importance of integrated health and care to their attention. **Other roles/networks:** Healthwatch, Swale Community Empowerment Network and Swale Patient Liaison Group alongside networks for the acute Trusts, community Trusts, IC24 and SECamb and related health/social care networks.

HELLO my name is
Su

My lived experience is as a carer, and I also have experience with the care workforce at home and in Housing 21 Extra Care Residence.

Key areas of interest: Brain Injury and Stroke, social care workforce and housing.

Other roles/networks: I am a local volunteer for Stroke Survivors and attend bi-weekly meetings. I am also a member of the Stroke Association and Kent Headway (Brain Injury Support) as a carer. I am also a shop volunteer at Pilgrims Libraries, Hospice and a volunteer IT buddy at Kent

HELLO my name is
Kerry

I've worked as an organisational development consultant for a local authority for 33 years. I have a 24-year-old son with a rare complex disability who, after attending a residential special needs college, now lives at home with us. We employ a team of carers through direct payments and also purchase day care services. Our son has been through children's, adults and the 16-25 transition social care teams.

Key areas of interest: younger people using social care services, transitions between services.

HELLO my name is
Lilli

I am a carer for my son who has schizophrenia (for 12 years) and currently lives in supported housing. He is on section 117 and has a care package including regular social care visits organised by his care-coordinator.

Key areas of interest: younger people using social care services, mental health, housing.

HELLO my name is
Sarah M.

I am a long-term mental, physical and social care service user with over 10 years of PPI experience.

Key areas of interest: advocacy for people with Autism and/or in criminal justice system.

Other roles/networks: I review services for the RCPsych and have many other experiences of PPI work.

HELLO my name is
John P.

My introduction to Care followed my involvement with our local Patient Participation Group, and subsequent membership of the Kent County Council People's Panel, which led to the opportunity to join this Project.

My role in the project as a joint applicant is all about ensuring public engagement and undertaking the role of lay representative. As a member of the main team, I have a voice in all areas and will always ensure the public are a key part of our working with co-production being addressed at all levels.

Key areas of interest: Integration of health and social care, including technology as I have a background in IT. Social prescribing and other developments helping to change culture to meet the needs of users of people in communities. **Other roles/networks:** I have various roles in health and social care groups in my local area and the Kent and Medway ICS.

HELLO my name is
Ruth

I am interested in many aspects of social care and the well-being of all people. My husband has a wheelchair, so we are interested in housing

HELLO my name is
Sarah G.

My lived experience is through caring for my mother who had Vascular Dementia. Also, I am supportive friends with parents/partners with

24



Lived Experience Group Meetings

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HELLO my name is
Ruth

I am interested in many aspects of social care and the well-being of all people. My husband is in a wheelchair, so we live in a sheltered housing community, and this has really made me realise about older people who are struggling with isolation and other mental health.

Key areas of interest: well-being and mental health and supporting all people with addiction.

HELLO my name is
Sarah G.

My lived experience is through caring for my mother who had Vascular Dementia. Also, I am supporting friends with parents/partners with Alzheimer's, so have an active interest in how their social care could improve. Additionally, I have research experience involving people with dementia, as whilst caring for my mother, I involved my mother and friends' parents with dementia in my designs to improve their quality of their lives, whilst studying my BSc in Computing and Design at the Open University.

Key areas of interest: Dementia, data and digital innovation

Other roles/networks: Currently I am a public advisor for ARC Kent, Sussex and Surrey for the Digital Innovation Theme, as well as being a volunteer for the Alzheimer's Society Dementia Voice Team. I am also the public advisor for the SHCAB IG & Data Access Group based in Kent.

HELLO my name is
Collette

My social care experience is both personal and professional. I oversteer care of my young brother who has autism spectrum and help to care for my goddaughter who needs 24hr support. I have also worked in social care since 2005 and was registered as a manager of services for young adults with learning disabilities, mental health issues and complex behaviour and needs. I am now the business development manager for the same company and oversee all referrals to our service.

Key areas of interest: Autism, learning disability, mental health, DoLS

Other roles/networks: I was a mentor for Canterbury Christchurch mental health students for their learning disability placements for 10 years.

HELLO my name is
Paul

I have both personal and professional experience. I am a qualified counsellor and used to do Street Pastor work. I am very interested in enabling people to be involved in their communities as much as they want to. I used to work as an expert patient trainer to help people take charge of their own disabilities and learn how to cope with challenges.

Key areas of interest: direct payments, personalisation and trying to help disabled people recognise and achieve their full potential. **Other roles/networks:** I am a member of the direct payments group at KCC and involved with ARC KSS Social Care Theme. Also involved with Wheelchair Group and People's Panel in Maidstone. Equipment Services.

HELLO my name is
John G.

After moving to Kent in 2007 I decided to do some voluntary work and was invited to join a new patient voice group called LINK. After joining I became aware that it was a new statutory organization to listen to the patient's voice (which later became Healthwatch). This organization opened many doors into health and social care services. As I and other members became more and more trusted by parts of the NHS and social care organisations, the list of invitations to join other groups grew like topsy which is how I joined this partnership.

Key areas of interest: Making sure health and social care work for everyone. Part of my work with Healthwatch involves a role in the process which very importantly includes equality of access for or all, and also the scrutiny of service specifications.

Other roles/networks: I am currently involved in both Healthwatch Kent and Healthwatch Medway alongside KCHFT, KCC – especially the Esther coaching project, IC24 and SECAMB. I chair my practice PPG. Occasionally I help individual patients to navigate the system.

HELLO my name is
Julie

My personal experience is as a carer of both the young and elderly – of a young person with semantic pragmatic language disorder whose social care support differs to that of my elderly mother who has mobility difficulties and is severely sighted (registered blind).

Key areas of interest: young people over the age of 18 who have communication difficulties or are neurodiverse. Interested in changing the view of social care as just personal care as it is very much about social support to allow people to live a fulfilled and happy life.

Other roles/networks: parents who care for young people over the age of 18 who have similar concerns to the type/ amount of social care and support their children will get after education or after they die.

This is not your usual PPIE!

It's PPIE in Research Capacity Building



Evaluated 3 ways:

- Impact log
- Bi-annual survey
- CUBE evaluation

Working Group Activities

01



Shaping Direction

- Event content & structure
- Regional ASC priorities



Refining Roles

- Researcher-in-residence remit
- Fellowship funding panel

02

03



Supporting Fellows

- 1:1 advice pre-submission
- Recruitment/data strategy feedback
- Steering group membership

05



Creating & Curating Content

- Newsletter authorship & review
- Blogs / website content
- Talks / conferences

04



Building Inclusivity

- Digital platform access refinements
- Accessible meeting formats

06

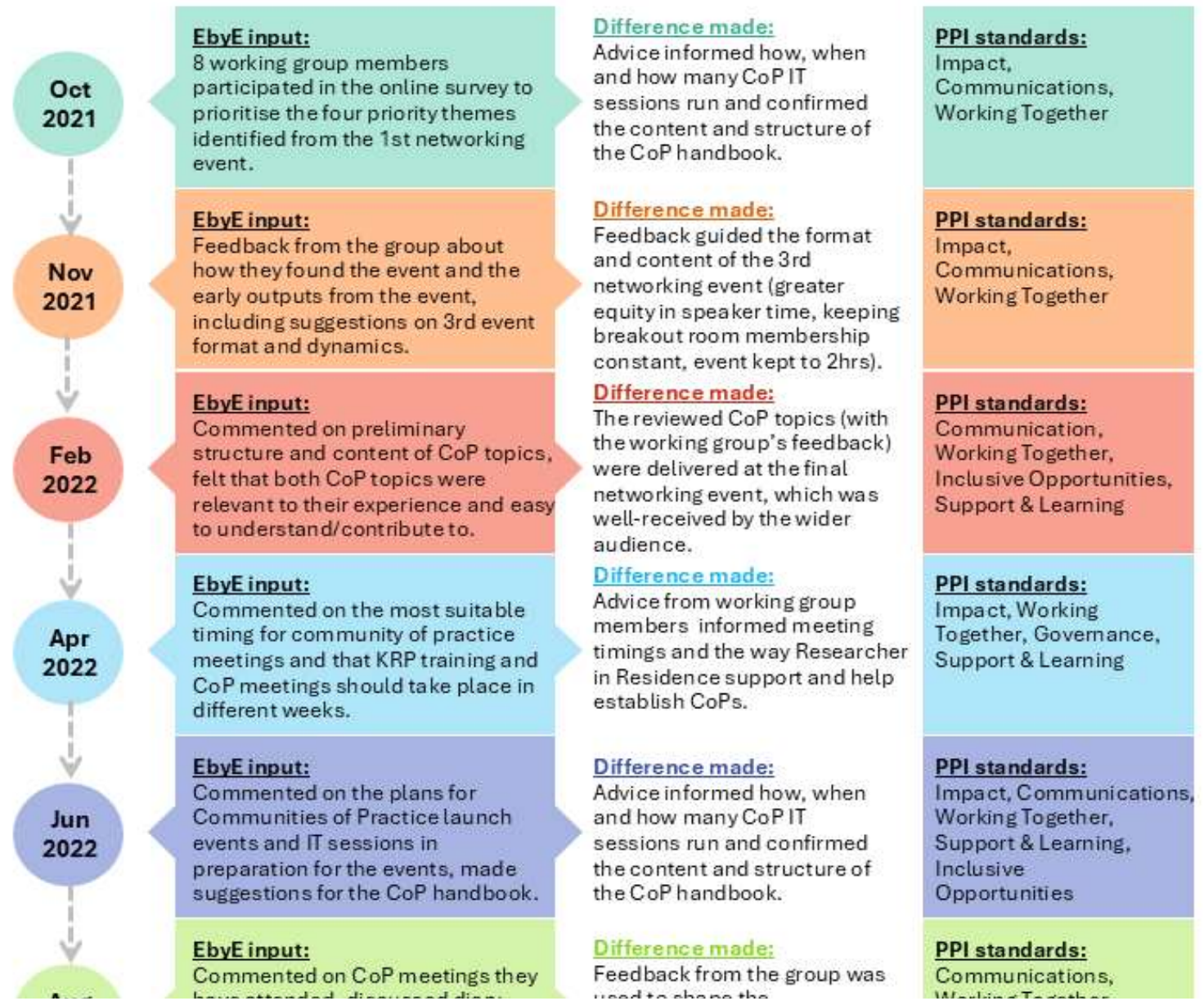


Influencing Systems

- Communities of Practice
- House of Lords call for evidence
- Impact evaluation guidance

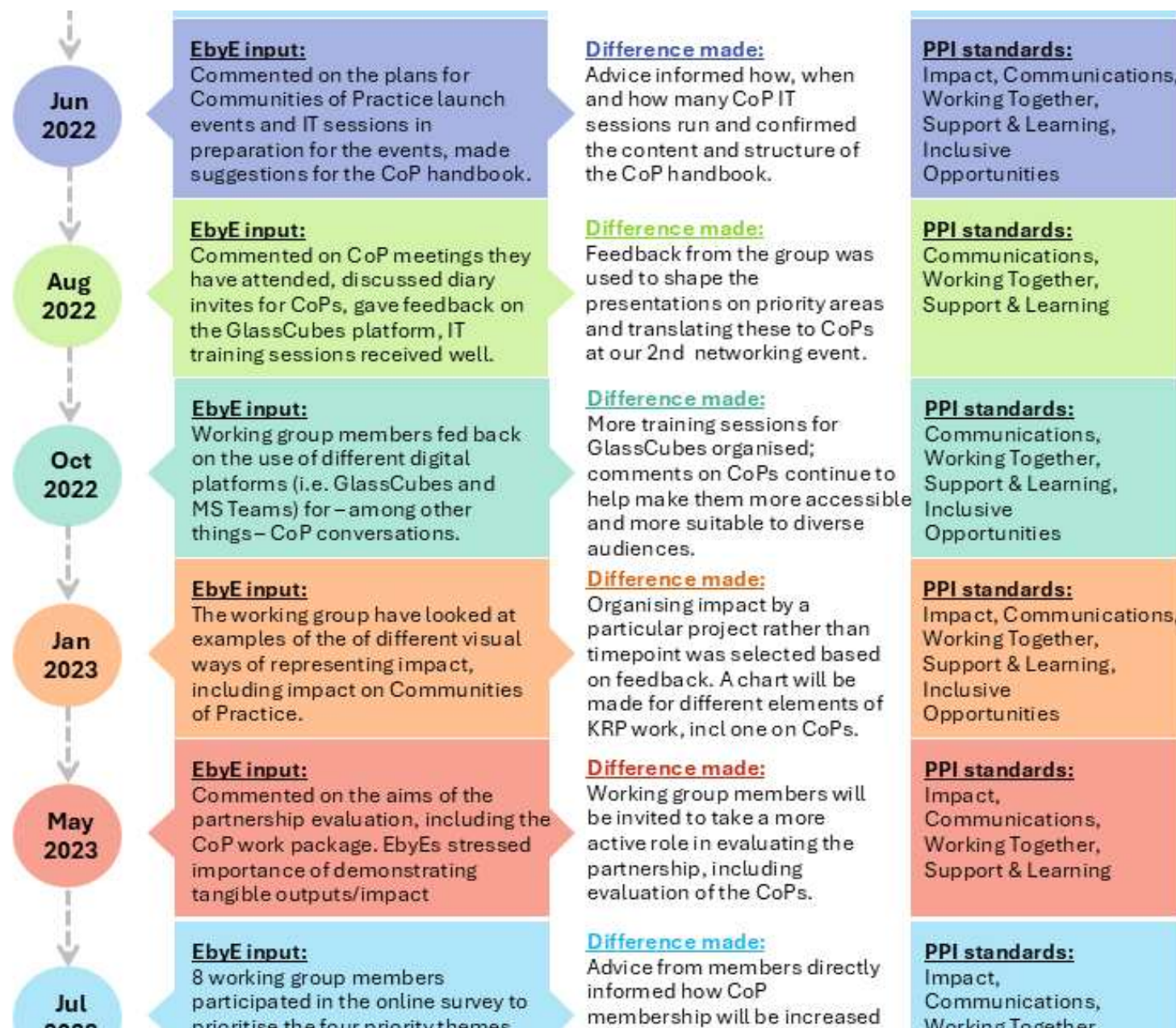
Impact Log

Capturing benefits to the partnership



Impact Log

Capturing benefits to the partnership



Bi-Annual Survey

Working group
experiences and
desired
improvements

Benefits to self

“Having given up work to care this project allows me to carry on using my brain again. Part of a team. Caring can be isolating and at some points quite monotonous, so it is nice to have something to work towards” (EE_T1_R5)

Iterative improvements

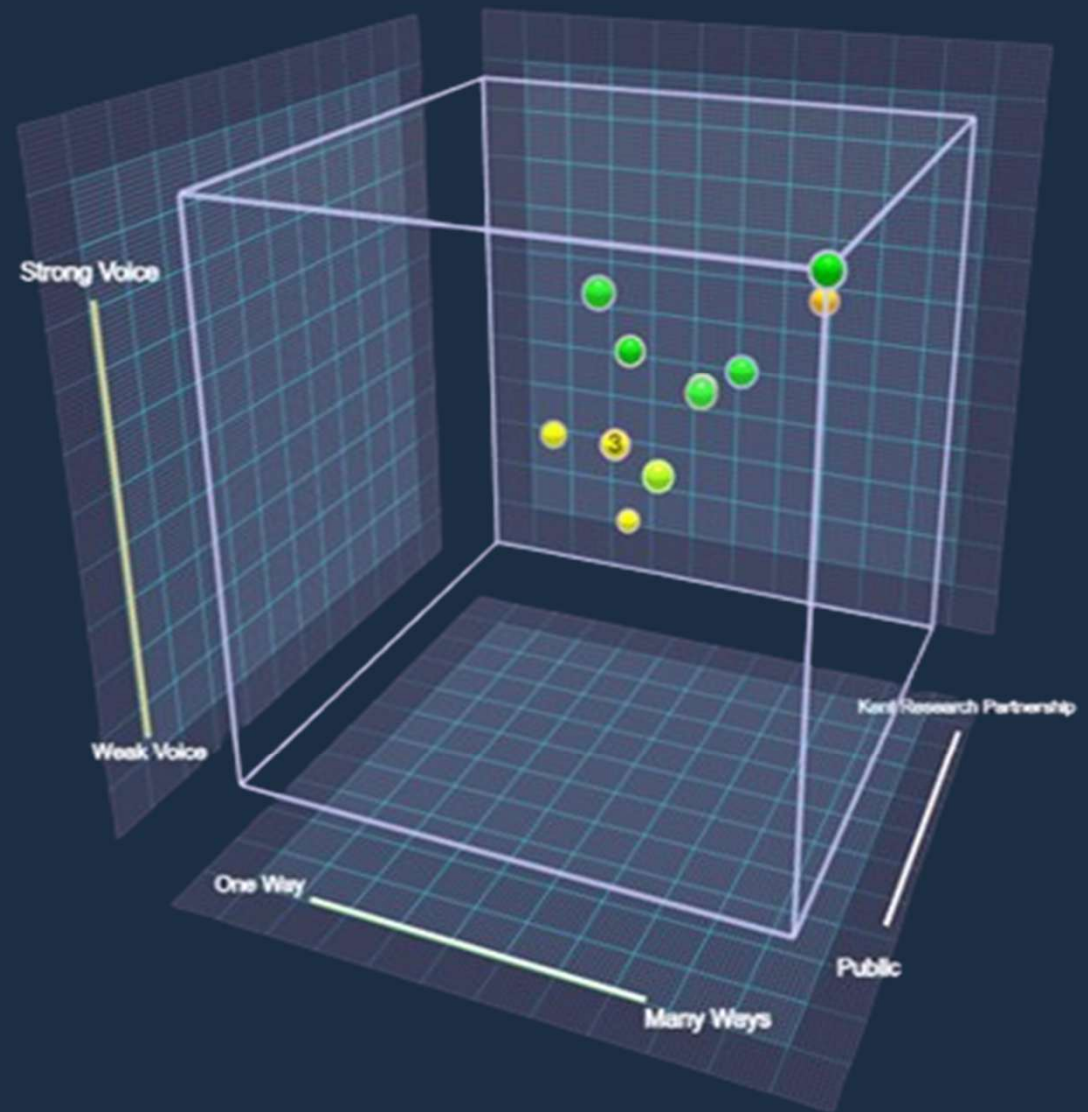
“It would be nice to see a wider range of ages of carers and cared for represented in the group. Young people should have a voice in their future care and this is the place for them to be included” (EE_T1_R2)

Lessons for the future

“To date progress has felt slow, but as more bits of the process come together, progress seems to be accelerating” (EE_T1_R4)

The CUBE

Evaluating quality,
interaction and
power





Key Message #1

**Impactful EbyE involvement
is ACHIEVABLE in adult
social care research
capacity building initiatives**





Key Message #2

ITERATIVE EVALIATION is crucial for identifying and addressing challenges as they occur





Key Message #3

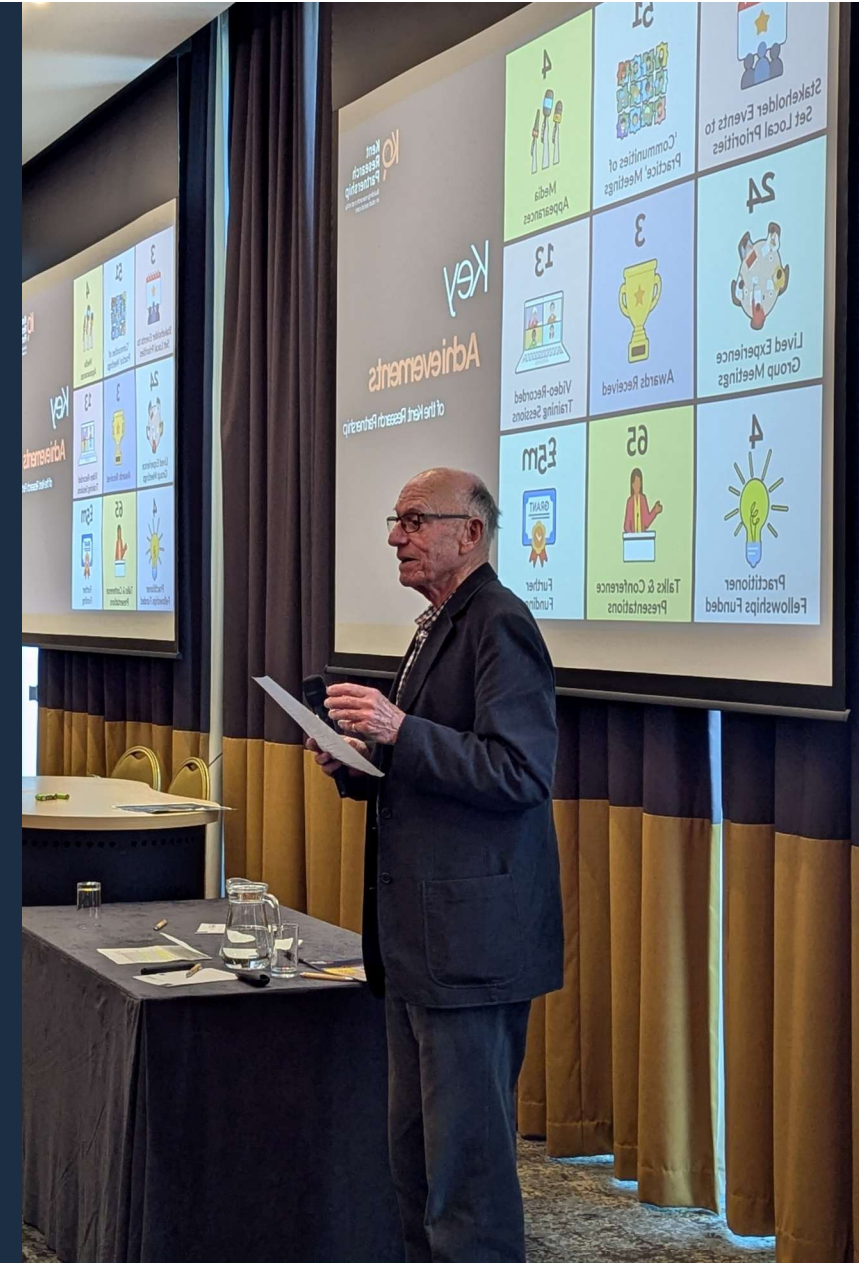
MULTIPLE METHODS may be needed to capture different types of impact for a variety of beneficiaries





Key Message #4

Research capacity building
in (Adult) Social Care is
DIFFERENT from healthcare





THANK YOU!

