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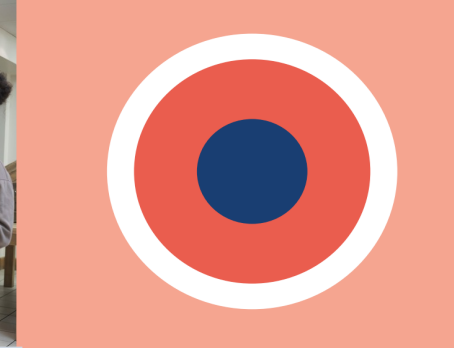
East of England Carer Research Network
Meeting Summary

Inaugural Meeting
14 February 2024
13:00-14:30 via Zoom

EoE Carer Research Network

Who is this for

- People interested in supporting unpaid/family carers in their role
- Carers, people who work with carers, researchers who explore carer experiences and how support can be improved

Aims

- Raise awareness of breadth and depth of unpaid/family carer research
- Provide opportunities to contribute research ideas so the most important questions are prioritised, and get involved in research
- Promote inclusion of carers and carer perspectives in health and social care research
- Grow carer and carer-inclusive research in East of England that will make a difference

Attendees at inaugural meeting

- Carers, those with third sector experience, general practitioner, researchers with personal caring experience, researchers and clinical research support

Nominated interest areas (pre-meeting)

Support in carer role and carer health and wellbeing

Navigation of services and systems, caring activities (e.g. hydration and toileting, care refusal), voice and rights in social care
Looking after all aspects of health and wellbeing, how to make support accessible
Family-focused practice, supporting conversations within families

Supporting workforce to support carers

New workforce roles (e.g. Carer Support Nurse pilot), service development to support carers, carer role in hospital discharge, actively involving carers in care planning, general upskilling of workforce to involve carers as active partners

Shared and unique experiences of carers

Carers are a diverse group: older adults, young people, spouse, parent, sibling, child, friend, from a minority ethnic or community group, in paid workforce, managing own health concerns, rural, LGBT+, provide care but not a "carer"

Discussion groups

Discussion topic 1

Supporting carers in their role and with their own health & wellbeing

Discussion topic 2

Supporting workforce to support carers

Three questions to discuss for each topic

1. What are your top priority areas/burning questions/areas of concern?
2. How can we promote participation in research design and delivery to include a wide range of voices and perspectives? (Patient and Public Involvement, investigator)
3. How can we promote participation in research to include a wide range of voices and perspectives? (Be a participant in research)

1. Supporting carers in role and own health & wellbeing

Defining and understanding carer role

- When do carers become aware that they are carers and "take on" the label? People don't know they are a carer until they look back.
- We need more proactive services for carers, to address fragmentation of services, and promote single point of care.
- How can we raise awareness of carers and their needs amongst health & social care (health in particular) and general public?
- Carers don't feel listened to, are sidelined and ghosted. Pronounced when family member has serious mental illness.
- Fear of the label of 'young carer' among parents (who are the "cared for").
- Need to think about how to identify and engage with carers, especially those amongst more stigmatised groups. How to support more diverse communities, culturally diverse, cultural obligations.
- Discharge from hospital, and discharge to care homes, are one of biggest stresses.
- A lot is known about hospital discharge already, but nothing changes – don't need more evidence, need to understand how to get evidence into practice.
- Resilience of third sector of concern (e.g. Norfolk Carers gone into liquidation). Third sector constantly drained.
- Issues around social admission – unfunded care.

1. Supporting carers in role and own health & wellbeing

Own health and wellbeing and what outcomes matter

- Impact of caring on income: the importance of having a job is massive, living wage, employers strapped for cash, impact on carers, not being able to take time off (zero hours contract). What does wellbeing mean for this person? (depression, suicidal thoughts). Carers having to hold everything together, fear of being evicted. Effect on benefits.
- Mental health of carers, this is a very serious issue
- How to select good outcomes? "Make a difference", noting that a good outcome can be different for different carers
- Outcome can be death – how to make it as positive as possible.
- Context is so important: what experiences (outcomes) are *shared* between carers and what are *unique*
- Carers give up valuable time to research, but nothing changes. Prioritise impactful research, that makes others want to join in and take part.

2. Supporting workforce to support carers

- How the networks that carers form as part of caring "work" (or don't work), who helps and what they do, it is all about relationships and understanding these.
- Caring as not just one on one but as relational, across a wide range of people caring for each other. Health and social care professionals only talk to one person at a time and miss out on this network aspect.
- Pressure on carers due to lack of psychiatric nurses, learning disability nurses, social care staff etc.
- Do health care staff know how to support carers – i.e., how to identify them and use the available tools and resources to support them? Supporting staff means giving them the resources and confidence to use tools to support carers.
- Do health / social care and voluntary sector understand what carers do, is there awareness?
- Need to recognise the value of at least starting conversations – even if the need cannot be met (conversations are in themselves supportive).
- Need to give carers a political voice.
- Produce a 'cartoon' diagram of 'pathway', what can carers access (allowances), very simple guidance and outcomes.
- "Workforce" includes educational workforce in schools, to recognise and support students who are young carers.

Meeting wrap-up and next steps

Final thoughts from a carer and a researcher

Carer had a lightbulb moment at the end of the meeting – you can be a carer for multiple people at the same time, and caring for a person with mental health challenges is also being a "carer".

Researchers never tire of hearing carer stories that give us material for us to take action on. Researchers need to think about how to turn their stories into material that turns heads and gets actions happening.

Next steps

Group agreed to meet as needed, consider quarterly. Next meeting to focus on types of outcomes that are valued by carers in health and social care research.

Next meeting: 12:00-13:30 20 June 2024

For further information on the Network: **p.fordham@uea.ac.uk**