

East of England Carer Research Network What Outcomes Matter?

Meeting Summary
20 June 2024
12:00-1:30 via Zoom



Discussion groups: topics

- **Meeting agenda**
 - **Discussion topic 1:** outcomes for carers and those they care for.
 - **Discussion topic 2:** outcomes for workforce and system partners.
 - **Three questions to discuss for each topic**
 1. What outcomes are most valued, from your perspective?
 2. How might these be collected?
 3. How would you want these outcomes communicated/shared?

During the meeting the group decided that two separate discussions were unnecessary. This is because what was coming out of the first discussion covered outcomes for all stakeholders mentioned above – workforce, system partners, carers, and those they care for. This highlights how outcomes for all groups are interlinked.

The following slides summarise the network's answers to the three questions above.

Question 1: What outcomes are most valued, from your perspective?

Theme 1: Integrated service support

- **Collaboration and communication between services**

Integrated Care Systems need to collaborate better to ensure a more co-ordinated response across social services, health and education systems. This can only be achieved by better communication.

Currently, transparency and communication within – and between – NHS Trusts/Local Authorities/Integrated Care Boards is incredibly fragmented. Even those volunteering within these organisations, including as board members, have no idea what's going on with caring. This shows there are not enough staff on ground to do the job.

Until this is addressed, there will still be issues with benefits, care, health needs, and capacity. These lead to a ripple effect impacting not just carers and those they care for, but whole families. It also affects how well professional stakeholders can do their jobs.

Question 1: What outcomes are most valued, from your perspective?

Theme 1: Integrated service support (continued)

- **Our discussion of how to address issues with collaboration/communication between systems focused on:**
 - **The need for a central information hub for carers.**
 - A single point of contact where all resources are gathered (e.g., through an online hub), carers would be able to get the advice and help they need in one place.
 - This would mitigate the extreme stress carers experience of having to go from pillar to post and be told “try this number for X”.
 - **The need for a named professional working with/supporting carers on future planning, as well as safety/emergency planning.**
 - This could be through a care-coordinator type role, with the professional able to access information from all relevant agencies (social services, health, education) involved in an individual’s care.
 - Like the information hub, this role would support carers by reducing their administrative burden and ensuring more effective integration of services.

Question 1: What outcomes are most valued, from your perspective?

Theme 1: Integrated service support (continued)

- **Assessment of carers' own support needs**

There needs to be a better and more coordinated response to factors that may impact on carers' capacity to care/ their own support needs. These may include:

- **Carers having multiple responsibilities** (employment, others to care for, any health issues)
- **Family systems** (psychological, family dynamics, social resources)
- **Cultural factors**
- **Wider social inequalities** (educational, financial, access to internet, having English as a second language etc).

Question 1: What outcomes are most valued, from your perspective?

Theme 1: Integrated service support (continued)

- **Discharge from hospital**

There is a huge gap here. Hospital staff do not alert those at home about impending discharge. Discussion identified that this can be traced back to:

- **Information systems:** GPs are the first point of contact, yet there is nothing on their screens alerting them to peoples' care situations at home.
- **Awareness:** lack of information/awareness means clinical staff don't consider partners/spouses and their roles as carers. They only think about the person in front of them.

Question 1: What outcomes are most valued, from your perspective?

Theme 2: Young carer awareness

- **Schools as partners**

As an important hub for young carers, it's important to find a better way to liaise with schools. One way to do this would be tracking how they get data about outcomes for young carers. We know of at least one school with a young carers lead but would like to know about more so we can follow this up and measure impact.

- **Issues for children at school**

We discussed issues with attendance and behaviour in schools and how these can be linked with burnout. We recognise any interventions addressing these should be linked with economic outcomes, i.e., "if you spent money *here*, you would be saving money *there*". We should link this to the fact carers save services money and that schools have a role to play. Whilst school budgets are for school-based improvement of outcomes, it is important to show what would happen without intervention and how this would affect schools.

Question 1: What outcomes are most valued, from your perspective?

Theme 2: Young carer awareness (continued)

- **Family dynamics**

A key consideration is the ecosystem within family/extended family – relationships between family members, siblings etc.

Theme 3: Data

- **Who to get data from**

At the last meeting we mentioned potentially creating a visual pathway of how to navigate the system. It was agreed the Carer Research Network could work together and help to progress this and that this will be discussed at our next meeting.

Question 1: What outcomes are most valued, from your perspective?

Theme 4: Status and power

- **Status**

The only way to achieve meaningful change is to raise the status of carers. One carer of 30 years commented that “*many people speak for us*” and the same problems are discussed over decades, yet there is no change from year to year. Carers need to be at the top table making decisions.

- **Structure of the NHS**

Carers are frustrated with the way their input is included (or not) in NHS policy and believe this is down to complicated management structures and people dropping the ball.

For example, People Participation Leads are supposed to address carer needs, however they feed into another tier of management. By the time issues get to the top, lots of time and money has been spent, leaving carers frustrated.

Question 1: What outcomes are most valued, from your perspective?

Theme 4: Status and power (continued)

- **Carer wellbeing in its own right**

Carer organisations say that projects addressing carers' needs are conflated with patient safety, with nothing aimed at carers alone. Whilst the analogy of 'power-sharing' in patient safety is important, carers agreed that it is essential that they are identified as having needs of their own which need to be addressed. This vision was supposedly advanced through the 2014 Care Act, yet things getting worse, not better.

Carer safety as a separate concept to patient safety is essential as:

- There are psychological issues with care and it is concerning that these issues have not been resolved.
- Participants were not sure how to make carers more visible. With research as a tool, it is important to make sure discussions like this go into the research so carers get the recognition they need and any new issues are identified, not just those that have existed for many years already.
- Participants were not sure how to ensure all the research has a meaningful impact.

Question 1: What outcomes are most valued, from your perspective?

Theme 4: Status and power (continued)

- **Challenges for researchers**

Topics discussed related to impact and design, such as:

- Making sure that we are asking questions that are important and interesting to carers. This can be done through co-production. Organisations such as Carers Voice co-produce as much as possible to represent carers' needs and opinions.
- An All-Age Carers Strategy should be interwoven into future projects. Carers Voice are currently working on this for Norfolk and Waveney. Discussion mentioned it is important to include how to access support, what's available, and what the priorities are. This should be co-produced and led by carers.
- Making sure there are carers at ICB presentations.

Question 1: What outcomes are most valued, from your perspective?

Theme 5: What worked, what can we seek to replicate?

- **Carer Support Nurse role in Great Yarmouth and Waveney**

This is a great example of an intervention that helps prioritise what money is spent on. Carers can be heard and allowed a space where they can say what they need.

- **Co-production strategy**

This needs work, both to figure out what to do next and how to make people listen.

- **New project**

Members of the network have secured funding for a 3-year project with Healthwatch Norfolk and carers of those with Serious Mental Illness (SMI). There is a lot of hope around the power of stories to move mountains.

Questions 2 & 3: How might these outcomes be collected, communicated and shared?

Theme 1: most impactful ways to collect, share and communicate evidence/concerns

- **Young people's groups**

These should have young people (and their parents) at the heart, such as including work based on their evaluations and having them on the board of trustees. In doing so, their voice will drive development and change.

- Regarding young people's organisations in Norfolk, a positive is that many have been around a long time and know each other. They've worked together to support families by taking young people who support their parents, as well as sibling-carers and carers of children with disabilities.
- However, competition for funding in Norfolk makes it harder to work together.

Questions 2 & 3: How might these outcomes be collected, communicated and shared?

Theme 1: most impactful ways to collect, share and communicate evidence/concerns

- **Patient Experience meetings**

The main issue discussed is the need to know what is going on. Participants shared that at Patient Experience meetings there is a repeated plea for transparency about what happens. They believe it could be an efficient and informed service, but there is no clear overview, transparency, or communication strategy.

- This is important to address as carers are in unique position to participate and contribute in a valuable way to these meetings.
- This is because they really know what is happening on the ground. Carers are in unique position to know what works.

Meeting wrap-up and next steps

Next steps

- **Young Carers**

There is a lack of funding for local data collection. This could be a future bid from members of the Network potentially focusing on research impacts and/or the local picture compared with national statistics (Norfolk in particular).

- **Carer Support Nurse**

There are ongoing opportunities for promoting the evidence base of the Carer Support Nurse role. These will be discussed at the next meeting.

- **Carers Voice working on All Age Carers Strategy**

One potential area for the Network to support is in the development of a Carers Pathway infographic.

- **Identifying common goals**

- Raising awareness amongst commissioners/systems that carers' needs and wellbeing should be amongst our top goals.
- This can be achieved by showing how carer-led/focused interventions make commissioners' jobs easier. Health economist colleagues could help with tools and ways to show trade-offs.

Meeting wrap-up and next steps

Next steps (continued)

Carer Research Network 2024-2025: Developing a Strategy

The network steering committee will develop a draft 12-month action plan which we will present for feedback and discussion our next meeting – to be advised by end of 2024. This action plan will detail how we will:

- raise awareness of unpaid care research
- grow the network
- select one or two projects to progress (with input from different ARC EoE themes and local stakeholders)
- plan a showcase face-to-face event next year

For further information on the Network, please contact p.fordham@uea.ac.uk