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| Document Title | Questioning Carers - Summary |
| Number and Category | 10e. Category E: SPIN-D - Developed Resources |
| Status | Final |
| Date | 26.06.2024 |
| Next Actions | |
| Developer (2a) | MF: TIDE |
| Contributor / Reviewer (2a) | Tide – Research Carers Group |

## Questioning Carers: Co-producing research with tide's Research Carers Group

### Introduction

In this resource, tide outlines the questions and ideas of its Research Carers Group to get carers and researchers talking. Carers' experiences before and after a diagnosis of dementia, the kinds of support they value, its availability, their routines, resources, problem-solving and the sense they make of their circumstances are all relevant to researchers.

### Here are some perspectives from the Research Carers Group

- *We could identify subject-worthy studies*
- *I was pleased to be invited to be a "research co-applicant" about a topic in which I have a keen interest. It was disappointing to be told that it was no longer possible because the position hadn't been funded*
- *I got in touch because I thought the research sounded interesting. I haven't heard anything since*
- *At the time I enjoyed it. They were very friendly. Then that's it! You hear nothing. You're not valued*
- *You are giving up your time, thinking time, to prepare and give the best answers you can to make your issues clear. You think about what you want to be asked and about what's important to you*
- *How relevant is it* [this research] *to the lives of carers and people with dementia?*

Tide's Research Carers Group knows that building openness and involvement into developing ideas and research design from the outset would reduce frustrations concerning research infrastructures and processes. There is so much to be discovered at all stages of research when carers are involved.

### Here are some questions

**Why do Research Councils and commissioners decide what researchers should be doing?**

Why not:

- *involve the carers of people with dementia in deciding what topics should be researched, most particularly if these are about carers. If research funders were open to alliances with the carers of people with dementia they may be better prepared to consider the perspectives of partners, parents, siblings, children, colleagues and friends to influence research topics.*
- *demonstrate the significance of carers, perspectives by creating a long-term programme of engagement to share in discussion and negotiation.*

**What does "co-producing research" mean to Research Councils, to commissioners, researchers and the carers of people with dementia?**

Why not:

- *think about building consensus about what co-production in research could look like. At best it is a dynamic process which brings carers and researchers together to learn. It involves funding and clear expectations*
- *ask for feedback from carers who have responded to invitations to participate in research as carer-researchers, as advisers or as participants*
- *ask about the job descriptions, the terms and conditions, the supervision of carer-researchers and peer support*
- *make sure that the research infrastructure gives priority to ensuring that carers receive timely payments for their contributions; puts people with shared interests in touch with each other; provides directories of key individuals involved in the research; ensures regular communication as the research progresses; and provides supervision*
- *encourage carers to shape research activities and descriptions of these so that information and materials are interesting and usable by carers and others who are not involved*
- *encourage all members of research teams, including carer-researchers, to keep diaries of their experience of co-producing research.*

**Why are researchers are still looking for carers as "representatives"?**

Why not:

- *be clear about how and why carers are being recruited.*
- *accept that:*
    - *carers look after people at different stages of dementia in a wide range of circumstances. There are current and former carers.* ○ *carers are at different stages of developing expertise.* ○ *carers' membership of support groups enables researchers to source carers.*
    - *there will always be voices that are unheard.* ○ *single carers or small groups should not be expected to speak about the exact experiences of all carers since ethnicity, service under-provision, gender, sexuality, age, digital*

*inclusion and poverty, for example, bring worlds of difference, experience and knowledge.*

**Why do Research Ethics Committees, whose job it is to ensure that the well-being of participants is prioritised, operate independently of carers' organisations?**

Why not:

- *explore ways of sharing the ideas and commentaries of carers with Research Ethics Committees. When tide's Research Carers were invited to consider research proposals their discussions are compelling*
- *think about the relevant Committee inviting carers' commentaries and feedback after they have contributed to a specific research activity. It may trigger careraccountable ways of working.*

**Finally, because there are opportunities for carers to be involved in different ways in the different stages of research…**

It is important to:

- *acknowledge carers' expressed interests.*
- *be in regular contact with carers, perhaps via regular briefings or newsletters.*
- *make the language of research inclusive and accessible.*
- *be honest about how the research "fits" with previous research, professional practice, regulation and government policies and priorities across the UK.*
- *build a supportive infrastructure, including contributing to the education of health and social care professionals and policy consultations, for example.*

**Carers want to see improvements in the lives of people with dementia and the lives of carers. They can be passionate product champions of research.**