Document Title	Questioning Carers - Full
Number and Category	11e. 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: what together in dementia everyday (tide) has learned about co-producing research

Margaret Flynn, Ruth Eley, Roland Blackburn, Jo Bush, Carol Callaby, Janis Cottie, Ruth Graham, Anne Irvine, Mary Mitchell, Anne Ward Ongley, Joe Williams and Christine Wise

This resource is drawn from the rich discussions over the last year at tide’s Research Carers Group and the Young Onset Carers group. It will continue to evolve.

Tide’s aim in this resource is twofold: to outline ideas which require the attention of researchers who are starting out on projects and to fuel further discussion. This is not to suggest that previous and ongoing research concerning the carers of people with dementia is irrelevant. Carers are invested in understanding and developing the emerging practice of contributing to research. Their forays into research to date are attuned to some of its tensions and problematic features as well as its promise.

Introduction

A person’s diagnosis of dementia, their experiences and those of their partners, parents, siblings, children, colleagues and friends are part of the bigger picture of human experience. Although there are some similarities as people make sense of the disruptions that arise “before” and “after” a diagnosis, people’s contexts and circumstances result in unique accounts of efforts to limit the sense of difference from others.

Where people are in the life stage at the time of a diagnosis is a crucial consideration. It has profound effects on established roles such as parenting, being an economic provider and/ or providing support to younger generations, for example. As well as compromising expectations of the future, the diagnosis may result in huge changes in how people live their lives as they weather the gradual loss of independence and seek to establish some control and continuity with their past.

Tide's carer involvement network is the backdrop to thinking about the ways in which carers make their situations manageable and their ideas and learning about carers co-producing research. How research is conducted is a matter of interest because researchers have considerable responsibilities in terms of being honest about the risks and benefits arising from research; being attentive to research methods; and processes of consent, for example. Tide's learning will grow because there are many areas that merit exploration and development when the role of carers in research activities is considered. However, it is based on several years of tide's collaboration with carers (see Appendix). Their experiential knowledge, insights, compelling questions and desire to share their learning and "give something back" have all shaped tide's ideas about carers questioning researchers and vice versa.

It merits noting that the experience and ideas reflected in this resource will not work well in all circumstances. They are limited in biomedical studies for example. Tide has some experience of working with a large pharmaceutical company – not in terms of the drugs being developed – but in understanding carers' perceptions of the usefulness of types of medication for people with certain forms of dementia.

Beginning at the beginning: commissioning research

- *Why don't we steer research from our angle? - We could identify subject-worthy studies.*

To this question and statement, we would add: What inspires research councils and commissioners and defines the priorities and directions they want researchers to take? Who sets the boundaries of what are required dementia research topics and methods?

If there is a way of introducing more self-consciousness among research commissioners, then carers are keen to play a part. For example, it should be possible for research commissioners responsible for setting research agendas to insist on "carer involvement/ participation/ co-production" with some back and forth about what this might look like and how it may occur.

Tide is learning that there are narrow and expanded versions of carer involvement/ participation/ co-production in research. Different commissioning processes might identify ways in which research agenda setting tracks and reflects the interests of carers. For example, discussions with carers about their willingness to participate in research concerning specific topics and/ or to source carers in their own networks has occasionally resulted in bewilderment:

- [How confident may we be] *that best practices are identified from a caring point of view?*
- An invitation to source carers of people with dementia who are potentially suicidal did not identify anyone for research purposes. The resulting discussion challenged the ethics of this request and disquiet was expressed

at the risks arising from identifying individuals who may become distressed as they describe their experience. It raises questions about the availability and duration of post-interview support

- There are some taken for granted assumptions that carers can be on standby for in person meetings and interviews. *We need notice!*

SO, an expanded version of research commissioning would enable "Whole System Partnerships and Conversations." Potentially these would reach beyond researchers' published literature reviews and government policies to embrace research ethics as perceived by carers as well as the multi-dimensional nature of caring.

Carers and research co-production

Research co-production with carers does not refer to a single activity or arrangement because what is emerging would suggest that there is little consensus.

The diverse experiences of tide carers parallel those of the research community. One example has prompted tide to question whether the emergent practice of creating research co-applicants addresses the unequal status of carers' knowledge:

- *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 feel as though I'm begging to be paid.

Although having "a carer co-applicant" as a member of a research team may appear to be a magnet for research commissioners, drafting a research proposal generally involves all co-applicants and their respectful inclusion in costings. Arguably some energy should be spent thinking about the governance of research, that is, the scope of activities and their purpose, leadership, clear divisions of responsibility and means of communication, operational oversight, including the supervision of all members of the research team and clarity about decision-making authority.

SO, asking questions about the terms and conditions of a research carer coapplicant and how the role is likely to be experienced is likely to deliver better prospects for collaboration, understanding and learning within research teams.

It is unlikely that there is a blueprint for excellence in championing and recruiting carers as research co-applicants.

SO, inviting all members of a research team to keep diaries of their interpersonal journeys may sharpen the ongoing and future research practice. In addition, gathering the job descriptions and terms and conditions of carer co-applicants and inviting all co-applicants to comment on these would contribute to the development of greater credibility in research co-production.

The systems funding research, academic and service infrastructures have yet to demonstrate that equal priority is given to ensuring that carers' receive timely payments for their contributions.

SO, if carers as co-applicants are to experience their contributions to research activities as a joint venture, the lack of effectiveness in addressing the persistent challenge of adequate and timely funding requires attention at individual, research team, agency/ university and research commissioning levels.

Researchers and their socialisation

- *I got in touch because I thought the research sounded interesting. I haven't heard anything since// Although I was told I'd been recruited I'm still waiting to hear from them*
- *I only heard back from the researcher because tide got in touch with them and requested an acknowledgement// The researcher wrote "Sorry I haven't been in touch." By the time the researcher gets around to [reporting the findings] X will be in a home!*

Opportunities to become involved in different ways in the different stages of research are unevenly distributed. Expectations result from responding to calls for the participation of carers in research. The onus is on everyone to state with some precision what may be reasonably expected within clear timeframes.

SO, the readiness to encourage participation at different stages of the research process should be matched with a demonstrable willingness to be connected. Minimally, this should ensure timely acknowledgements, putting people with shared interests in touch with each other, providing directories, providing supervision, offering learning events, regular communications such as newsletters, and negotiated ways of sustaining people's interests, for example.

Some topics snag carers' interests more than others. One researcher invited tide carers to attend an in-person meeting. The topic generated a lot of discussion, not least because of its relevance to people's daily lives. Since it was not feasible for anyone to attend an in-person meeting, three carers undertook to draft some notes for the researcher and these were sent with additional insights from the group discussion. These carers remain interested in the topic and would like to be kept informed of its findings.

SO, (i) researchers might keep a directory of groups and individuals, and their contact details, so that their contributions may be acknowledged and they may receive information about the research's progress and findings; and (ii) tide might "follow-up" on researchers' requests to source carers so that it may direct carers to information about the course of the research; and begin to generate its own carer-led ideas for valued research questions and topics.

Some research programmes may have greater capacity to support co-production with carers than others. Typically, carers would wish to see better services in terms of their adequacy, effectiveness and availability. Although there is no merit in researchers claiming that their research will be instrumental in creating change, setting out how the research topic "fits" with, and complements. what is known so far in terms of

(i) previous research
(ii) professional practice
(iii) regulation
(iv) government policies and priorities across the UK

may provide some clarity, and humility, in answering questions such as, *Will anything good come of it? How relevant is it to the lives of carers and people with dementia? Will it make visible our pressing concerns about what is needed?*

SO, the forms in which carers' expertise may be reflected in research activities requires meticulous forethought and preparation. The confirmation of research funding is not the best time to think about adequate recompense for carers or the best ways of making research accountable to all.

Co-producing better researchers and carer researchers

- *Why are we educating researchers to be so inept?*
- *I'm sick and tired of teaching researchers about dementia*
- *Does no one proof-read the material researchers send out – including their letters?*
- *I've no idea what they're talking about!*

There are good reasons why researchers should never work in isolation. Working with carers in different circumstances *before* research and processes are designed could eliminate or reduce the likelihood of frustration and misunderstanding.

In an era of involvement, participation and co-production there are voices that remain unheard. The practicalities of juggling caring responsibilities with diverse arrangements for participation render it important to be specific about how carers are selected and how the necessity of flexibility is accommodated.

Carers are at different stages of developing expertise in caring for a person with dementia and in achieving some continuity with their histories. Some will be part of support groups and charities which may assist researchers in sourcing carers. It follows that seeking carer "representatives" places a single carer or a small number of carers in the impossible position of being expected to speak about the exact experiences of all carers. Those who have not joined support groups are effectively excluded.

SO, relying on an individual or a small number of carers in a specified research capacity should raise questions about how the carers have been recruited and the rationale for their inclusion. Building such transparency into research design is critical if themes such as ethnicity, service under-provision, gender, sexuality, age, digital inclusion and poverty are factored into considerations of equality and inclusiveness. Research teams are well placed to counter such damaging labels as "professional carers," as applied to the small number who are repeatedly invited to participate as experts.

Acronyms, hypotheses, sampling, triangulation, subjects, experimental design, treatment and control groups, qualitative interviewing, categories and analysis are shortcuts and terms which are part of researchers' vocabulary. Developing more inclusive research requires attention to the ways in which research is described and reported:

- *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*

SO, if the allocation of research resources favours the engagement of carers then there must be some consensus about the language which is used because it shapes thinking and behaviour. Even simple self-descriptions of *"the wife, husband, mother, son, daughter, friend, colleague of…//* [or] *a carer"* account for vast differences in the lives of those who support people with dementia.

Carers' willingness to share their experience in enhancing research activities is an asset, not least since this is likely to add to the credentials of the research. It has the potential to forge connections with those who are supporting people with dementia. However, the emotional terrain should be considered as people share experiences which are familiar to carer researchers. For example, how are carer researchers encouraged to be:

- cautious in what they share during interviews and meetings?
- non-judgmental when carers' statements challenge their own values and ways of thinking?
- researchers?

There are tensions too for research teams embracing co-production.

SO, attempting a radical transformation in the ways in which research is conducted, which immerses carers in educational experiences, requires a supportive infrastructure. For example, supervisors to encourage participation in interest-based, learning opportunities across disciplines and faculties; contributing to the education of health and social care professionals; and in contributing to local and national policy consultations. How research departments and teams engage in "succession planning" to enable the recruitment and development of new carer researchers would be instrumental in developing an infrastructure, in addition to exploring the obligations to co-applicants at the end of the research funding period.

Researchers are well placed to locate their research in the contexts of legislation, policies and service provision within the UK. Although research funding does not fund researchers to implement the recommendations or the uptake of research findings, where these involve evidence of effective interventions, for example, they matter a great deal to carers.

SO, carers can be product-champions of research findings and may bridge the research-policy gaps and the research-change-development gaps. Research has the potential to provide evidence that is consistent with improving the experiences of people with dementia and those of their carers.

There is a kaleidoscope of carer experience which remains to be factored into the health, social care, practice and professional training environments. The following quotations glimpse some of the pathways being negotiated, the consequences of under- resourcing carer support, people's personal interpretations, fury - and heartache - concerning the course of dementia. Tide shares the interest of many individuals and organisations in affirming the necessity of finding compassionate and better ways of responding to people's changing support needs – that carers themselves value and which evidence the necessity of change.

X is at the end stage, in bed all the time now, can't walk and talk but I learned today that X doesn't have a medical need so no Continuing Healthcare funding. I haven't slept for over 70 hours. You have to fight for everything//

We were told that my partner had dementia and then we were out the door//

[Clinicians] *kept saying that they wanted to increase his* [mental] *capacity//*

Last week I spoke to 13 different organisations//

I told the local authority about a [planned event] *and said "I want to be there." Even with plenty of notice there is no service to support my partner. I am sick and tired of my needs, my health and my mental health coming second place to my partner's needs…I feel so unbelievably angry//*

I had a Carer's Assessment and was underwhelmed//

It's like the early stages of widowhood. Something new, something else has gone. You are doing things for the last time and it's so sad//

SO FINALLY, discussion and research are required that ask questions about the short and long-term outcomes of co-producing research, the knowledge it generates and the standards by which it may be judged.

Conclusions

Attention to the marginalized standing of carers in research is long overdue. Necessarily there are research commissioners and researchers who have experienced dementia within their own families who will be familiar with the arbitrary and unaccountable ways that determine the services available. It is likely that their motivation resembles that of carers interested in securing improvements in the lives of people with dementia and their carers. The familiar self-effacement of being "just a carer" masks a world of experience. Research is one means of taking on carers' priorities and insights and the questions that matter to them.

Appendix

Backstory

Immersing tide's involvement network of current and former carers in research may be traced via inspirational connections and previously unforeseen paths – that is by:

- identifying ways of honoring the biographies of people with dementia[1] as well as the relationships, knowledge and talents of carers via the Life Story Network[2]
- glimpsing the open-ended consequences of carers negotiating assessments and support for the person with dementia, informing relatives and friends of a confirmed diagnosis, and preparing for uncertain futures
- gathering insights into the ways in which carers re-work their ideas about their identity as they find and manage ways of sustaining links with their lives before the diagnosis of dementia
- learning from its carer-facilitated, virtual groups; tide's online workshops; an advisory group of current and former carers;[3] and, more recently, tide's *Research Carers Group*
- enabling carers to channel their questions and experiences in professional education and training, conferences, workshops, policy development and responses to consultations
- encouraging carers to consider ways in which they may provide feedback on their experience of health and social care's availability and coverage; advise other carers of useful provision in their localities;[4] advocate for other carers; and participate in local and regional planning programmes
- welcoming opportunities to work collaboratively for better outcomes, for example, working with the Alzheimer's Society in Merseyside to develop peer support groups for younger people with dementia and their carers.

This rich history has confirmed tide's credibility as a charity that adds to the menu of what carers prioritise and value. Its work programme enables tide to draw themes and "starting points" from carers' stories. They continue to shape its activities as a versatile carers' involvement network.

It was the desire of many former carers "to give something back" that gave tide the confidence to invite carers interested in research to participate in a *Research Carers' Group.* Tide has experience of enabling carers to participate in research but the

---

[1] www.tidecarers.org.uk/join-our-network and P. Kaiser and R. Eley (Eds.) *Life Story Work with People with Dementia.* London: Jessica Kingsley Publishers, 2017

[2] https://www.tide.uk.net/life-story-work/

[3] See for example, https://www.tide.uk.net/living-grief-and-bereavement/

[4] See for example, https://dsdc.bangor.ac.uk/documents/knowledge-is-power-carers-en.pdf [5] spindementianet.org

opportunities arising from SPIN-D[5] has underlined its belief that carers are key to bringing research to life.

Before SPIN-D

Responding to random invitations to the carers of people with dementia, via tide, was the springboard to developing ideas about worthwhile research involvement. As tide has leaned further into research it seeks to ensure that:

(i) the involvement of carers is evidenced at all stages of the research process
(ii) their involvement is interactive and enabling
(iii) the knowledge and expertise of carers is acknowledged and funded
(iv) carers are provided with accessible, regular briefings and collaborative opportunities to discuss findings and their implications.

It follows that tide, as an inadvertent broker, has declined to support research involvement invitations where:

- there is an expectation that all contributions will be provided on a pro-bono basis
- they cover topics about which carers' acknowledge they have neither interest nor experience.

Taking part in research is one of tide's capacity-building programmes. It was developed initially with carers in Northern Ireland. It introduces participants to research processes, some of which they will be familiar with; in addition, the many stages at which carers may become involved in research and the different kinds of involvement are described; insights into the expectations of researchers and participants are considered; plus, the different ways of doing research.

In turn, this led tide's carers to identify some criteria for partnering with researchers. These draw on carers' experience, for example:

I. The usability and relevance of the proposed research to the lives and circumstances of carers. Tide carers may have raised and discussed some of the topics identified by researchers. One example concerns ongoing research by the TIMES programme to develop a primary care sleep management intervention. Tide carers are contributing to this as "experts by experience"
II. The readiness of the researchers to engage with carers as equal partners throughout the life of the research programme. For example, discussing the research purpose, how the research topics are defined and explained, the methods, the nature of involvement, the findings and recommendations. Adaptation and flexibility to ensure carers'

credible participation acknowledges their circumstances and demands on their time

---

III. Budgeted payments for the time and expertise of carers who contribute as experts and to tide, as a charity, in nurturing and supporting carers' participation
IV. The willingness of researchers to negotiate ways of acknowledging carers' contributions, e.g. as co-authors of publications
V. Assurance concerning General Data Protection Regulation, confidentiality and the consent process
VI. Researchers' investment in disseminating findings in freely accessible websites in addition to academic journals (for which subscriptions are required).

Such criteria shape tide's responses to requests for research involvement. Requests for carers' involvement in research are considered by the *Research Carers' Group* and, if timing permits, feature in the monthly newsletter to all carers known to its involvement network. Tide envisages that it will soon be in a position to align people's known interests with specific research opportunities.