Received: 30 September 2020 | Accepted: 6 September 2021

DOI: 10.1111/1467-9566.13374

ORIGINAL ARTICLE

SOCIOLOGY OF HEALTH & ILLNESS

Lived time and the affordances of clinical research participation

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Funding information
Innovative Medicines Initiative, Grant/Award Number: 115736; Wellcome Trust, Grant/Award Number: 206194

Abstract

In this article, we address the problem of participation and the dominant focus on motivations in clinical research. We explore participation as a relational mode of 'being in time' in Alzheimer's dementia prevention—a field profoundly shaped by changing bodies through time, as well as promissory trends towards future-oriented preventative medicine. Analysis of interviews with older adults in a clinical trial platform demonstrates that what research 'does' or might (not) 'do' for participants emerges as temporalities of participants' everyday lives become entangled with the possibilities, constraints and demands of biomedical 'research time'. As well as consistent desires to help (future) others, we identify incidental possibilities for care that emerged from continued research participation. We argue that longitudinal research participation can productively be understood as a set of evolving *affordances*: whereby differing limits and possibilities for care and agency emerge in a world where dementia cannot be cured. Future trial participation is considered in terms of 'therapeutic affordances', which are likely to fluctuate as certain lived or imagined futures unfold. As such, we open up a conceptual space to think about why, how, and critically, *when* participation happens, as it emerges in relation to lived times of ageing and everyday life.

KEYWORDS
affordances, dementia, motivations, research participation, temporality

INTRODUCTION

Across contemporary scientific and societal contexts, 'participation' has come to be known in terms of *problems*; of how it can be done better and why people are motivated (or not) to participate (Kelty, 2020). In this article, we propose a focus on the problem of participation as a mode of 'being in time' (Röck, 2019). This recognises that participation is an ongoing practice that interweaves with life beyond the study (Harries et al., 2019), which affords (cf Ingold, 2000) specific possibilities as the timelines of studies and participants' lives intersect. We demonstrate this through our analysis of interviews with participants enrolled in a longitudinal dementia prevention study, taking seriously the incidental and emergent possibilities that facilitate continued participation, as well as future-oriented hopes, concerns and aspirations associated with the research endeavour.

Through these steps, we bring together theories of affordances (Dokumaci, 2017, 2020; Gibson, 2014; Ingold, 2018) with work on the temporalities of research participation. We propose that this dual focus helps in three important ways, highlighting: first, the dynamic and changeable nature of research interactions *through time* that contribute to the initiation and continuation of participation; second, the *relational* interactions between participants and their (social, material and temporal) environments that make up participation and extend beyond simple costs or benefits to the individual; and finally, by shining a light on the *limits* as well as the *possibilities* of these interactions (in this case, the long-term engagement with biomedical research). This enables us to theorise the therapeutic *affordances* of future participation, which embeds the limits and possibilities of biomedical promise in the lives of particular participants. Our aim is that, through ethnographic attention to situations of opportunity and limitation in research participation, we can provide depth and specificity to the sociological and bioethical discourse around clinical research participation.

The problem of participation

The recruitment of clinical research participants has both expanded and intensified in recent years, and the identification and enrolment of the 'right' participants has become the subject of significant interest and activity (Epstein, 2008; Milne et al., 2018). When it comes to large-scale biomedical research, the problem of participation is often framed by clinical researchers in terms of individual motivations, barriers and facilitators at the point of recruitment. This in turn has sparked interest in studies "of what motivates older adults to participate in clinical studies" (Jefferson et al., 2011, p. 443), particularly in contexts where there are no clear treatment benefits associated with participating (Sano et al., 2018). Thus, the problem of clinical research participation is often framed in terms of individual motivations and episodic decision-making processes, albeit in relation to increasingly complex social and ethical issues.

Work in the social sciences, however, has troubled framings of participation in terms of individual decision-making and associated assessments of benefits or costs, instead emphasising the relational and contextual nature of participation. Thus, ideas of research participation as

altruism, or "free human gifts" (Titmuss, 1970, p. 385), have been unpacked and complicated by social science research (Olsen et al., 2020; Tutton & Prainsack, 2011). This work, while recognising the importance of the gift relationship to understanding participation in biomedical research, has also emphasised the relational and situated nature of participation (Locock & Boylan, 2016); that individuals are "socially situated and [their] interests are rarely purely self-interested" (Dove et al., 2017, p. 161). Dove et al. here echo earlier research that questions the extent to which motivations to participate pertain to the self or others (Hallowell et al., 2010). Others have foregrounded the wider social and spatial context of the research participant, as patient/citizen within the English NHS (Adams & McKevitt, 2015), and as part of the 'public body' of blood donation infrastructures (Cohn, 2016).

In this article, we too are interested in the relational and contextual aspects of research participation. However, we suggest that these approaches can usefully be extended by a more in-depth focus on the *temporal contexts o*f clinical research participation, including considering how framings and opportunities associated with participation emerge as ongoing and iterative achievements across the life course.

Temporal contexts of research participation

Although Ulrike Felt has argued for "[bringing] time to the forefront of debates on participation" (2016, p. 178), work in this line has often focussed broadly on public engagement with temporal orders of innovation and knowledge development. The temporal contexts of clinical research participation present us with the additional temporal order of *lived* ageing and the risk of being or becoming ill. They also provide a clear empirical field, compared to the vast and "all too flexible" areas of patient participation (Nielsen & Langstrup, 2018, p. 260) or research participation more generally. We focus on three specific temporal contexts. The first relates to the futures associated with participation, and the 'therapeutic promise' (Rubin, 2008) of research which, regardless of common concerns about 'therapeutic misconceptions' (Appelbaum et al., 1987; Lidz et al., 2015), affords particular possibilities to research participants. This may include a sense of control over future illness (e.g. Holmberg et al., 2015), as well as monitoring of current and future health, and close relationships with a clinical team (Locock & Boylan, 2016).

Furthermore, work by Hallowell et al. (2010) emphasises that motivations to participate are dynamic, revisited and refined in relation to the changing life circumstances of the participant, and that participants see themselves as positioned within a complex network of relationships in which their actions are tied to others in the past and future. Finally, there is increasing recognition that participation is ongoing and iterative. The decision to participate in research is thus not the matter of a single moment, but may be only one among a sequence of decisions to take part in research. While this has primarily been highlighted in relation to Phase I clinical trials (Edelblute & Fisher, 2015; Mwale, 2020), participation in longitudinal studies, cohorts or biobanks may also be only one stage in a participants' research 'career'. This is particularly evident in initiatives such as the US All of Us precision medicine initiative, cohorts that also aim to act as resources for recruitment into further research studies, or clinical trials (Collins & Varmus, 2015; Milne, 2018). This linkage of observational studies with clinical trials for novel treatments *in the future* forms the focus for this article.

To extend these discussions, we revisit the question of why people participate in biomedical research with the aim of situating the temporalities of research in the context of the lived times (Adam, 2006) of the lives and social worlds of participants. We focus on how participants

describe their research practice unfolding over time and intersecting with the lived experience of ageing. Our intention is not to separate lived time out from technical and scientific processes, but to open up ways that these aspects may work together to create changing conditions for research participation and what it affords. Our engagement with the affordances of temporal contexts thus draws out further the ongoing and shifting ways that people relate to clinical research participation. We add context and specificity to this analysis by situating it in a particular dementia prevention project: noting the ways, this research punctuates chronic lived states of being at risk of dementia, and the development of possible biomedical interventions.

The case: European Prevention of Alzheimer's Dementia (EPAD)

Our paper focuses on a domain, that of Alzheimer's dementia research, which is constructed around practices of tracking and intervening in changing bodies and brains over time, particularly in light of the shift to focus on prevention (Giovanni et al., 2019; Leibing, 2014). This approach to Alzheimer's disease is reflected in our case study, and corresponds with a wider biomedical preoccupation with identifying pre-symptomatic, or 'silent' illnesses, in the hope they can be pre-empted or prevented (Dumit, 2012; Kerr et al., 2019; Rose, 2007). Furthermore, in the context of Alzheimer's disease, which has few approved treatments, none of which have been demonstrated to be effective in preventing or delaying disease, research and clinical trials is understood to play a critical role in offering possibilities and promise for those who are 'at risk' or have symptoms suggestive of cognitive decline (Ritchie et al., 2017). This creates the condition for future-oriented, often speculative work when it comes to identifying the *right time* for the *right participants* to respond optimally to experimental drugs to prevent Alzheimer's disease (Brenman & Milne, 2021).

The EPAD (European Prevention of Alzheimer's Dementia) study, funded by the EU's Innovative Medicines Initiative from 2015 to 2020, had two aims: to study cognitive and biological change associated with Alzheimer's disease longitudinally within a cohort of participants; and to recruit participants from this cohort for Phase II clinical trials of drugs that may prevent or delay the onset of symptoms (Solomon et al., 2018). Phase II clinical trials involve the administration of a drug to a group of people with the condition it seeks to treat. However, these trials may not be randomised or large enough to show whether the drug is efficacious. Crucially, neither the study, nor the planned clinical trial offered evidenced treatment benefits to those who took part. Participants in the study came in for visits every 6 months to 1 year for neuroimaging, biological sample testing, and cognitive assessment to track the natural history of ageing and disease and to assess eligibility, or 'trial-readiness' for the future experimental drug trial. At the time we spoke to participants, the longitudinal cohort study had been running for approximately 5 years, in which new participants constantly being recruited. Future clinical trials were being discussed but none were underway.

A central feature of the EPAD project was an innovative design for the recruitment of participants for longitudinal research and clinical trials. Recruitment for the cohort study relied on the renewal of existing participation, contacting participants in existing research studies for *further* participation (Vermunt et al., 2018). The project then aimed to achieve swift recruitment for clinical trials by inviting eligible participants in the cohort study to take part in a clinical trial.

METHODOLOGY

In this article, we draw upon interviews with participants in the EPAD study cohort as part of a sub-study known as SPEAR: the 'Study of participant Experience in Alzheimer's disease Research'. This was a mixed-methods study that included a survey, which we will report elsewhere, as well as six months ethnographic fieldwork in four research facilities across the UK. As part of the ethnographic arm of the study, we conducted semi-structured interviews with 25 participants of the longitudinal cohort study. Interviews were either face-to-face (at clinical research facilities or home visit) or over the telephone (where participants were already familiar with the researcher from study visit observations).

The interviews lasted approximately 45 min and were loosely shaped around the research timeline, starting with a question about how they first came to be involved in the study, going to inquire about their experiences of continued participation, and ending on tentative questions around future trial participation and expectations. This was informed by the ethnographic observations, in which the qualitative researcher familiarised herself with the research process and encountered participants and researchers navigating a range of stages in this process.[1] The longitudinal cohort study provided an opportunity to understand the timing of participation across participants in a single study, and expectations for a future clinical trial. However, our study took place at a single time point between these two phases of the project, meaning our focus on evolving motivations and expectations was based on the talk of participants, rather than 'real-time' following of participants through the study.

We spoke to nine men and sixteen women, between the ages of 50 and 80. None had a clinical diagnosis of dementia, as this was an exclusion criterion for the longitudinal cohort study. Reflecting the wider study population (at least in the UK), the majority of participants were cognitively healthy, although we also spoke to people with mild cognitive impairment—a contested sub-clinical category which is nevertheless 'diagnosed' in memory clinics (Swallow, 2020). In this article, we focus on participants who had become involved via research channels rather than clinical referrals.[2] Reflecting the wider study population, the participants we interviewed were overwhelmingly White British, ostensibly of high socioeconomic status, and highly educated. Interviews were audio-recorded, transcribed and analysed on NVivo software. All participants were assigned a pseudonym immediately after data collection, which we use in the empirical material below. The design and implementation of the study was discussed with the EPAD research participant panel in one of the key study sites and feedback incorporated. The study received NHS Research Ethics approval (REC Reference 19/NW/0315).

We analysed interviews thematically, using an abductive approach to think through these data in relation to the temporalities of dementia prevention research, as described above (Tavory & Timmermans, 2014). Notions of biomedical research time (time as it is measured) and 'lived' time as it is experienced (Taylor, 2020, p. 90) were used as sensitising concepts in the analysis (Green & Thorogood, 2018). However, participation practices—and what they offered or afforded to people—emerged as bound to the *overlapping* temporal processes of the ageing experience and longitudinal research, often in non-linear ways. In the material that follows, we attend to lived time as it emerged in the data: as entangled with and shaped by biomedical research time. To highlight the temporal themes of iteration and future promise in clinical research participation, we have divided the findings into subthemes under two main parts: on continuity and on anticipation.

Continuity

Participants often discussed the *emergent* possibilities that research participation offered at their particular stage in the life course. This was a period of transition for many older adults: of being old enough to participate and therefore 'at risk' of developing dementia but mobile and active enough to be intensively involved in research, and without a diagnosis of dementia. It was generally understood amongst participants that participation could not in itself prevent the bodily and cognitive changes associated with Alzheimer's disease, which a *future* preventative treatment would target. Becoming a research participant was consistently described in terms of altruism and helping (future) others, both in interviews and our wider ethnographic and survey data, and the relational aspects of 'doing something for others' came out particularly strongly in interviews. Nevertheless, these older adults would also find themselves in situations where study participation played a role in establishing a sense of continuity of self as well as possibilities for care, now and in the future. The three aspects of continuity (of participation, role and body) that we explore below demonstrate how reasons for participating emerged in particular temporal contexts.

Continuity of participation: "in the loop"

The first temporal context that shapes reasons for, and possibilities of, research participation is the 'loop' of *repeat* participation and the rhythmic connections between past, present and future that this repetition affords. Participants often had a long history of being involved with medical research and became involved with EPAD via other studies. Stories of becoming a research participant thus reflected the position of biomedical research participation as a familiar repeating motif in participants' lives:

> "I think the answer is once you're involved in one research project people then, somebody says, 'oh there's this other research project I think you'd be interested in and we already know you're the sort of person that volunteers.'"
>
> (Denise)

Prior involvement in biomedical research was responsible for the recruitment of the majority of participants we spoke to, and in the cohort at large. These participants were recruited from registries of existing, and thus potential, participants who were eligible and willing to be contacted. We also observed a material familiarity with research spaces: participants talked about other studies that had taken place "down the hall" or in the same hospital, or their previous careers in science and medicine (something we expand on below). These research participants had previously demonstrated a willingness to 'give' time and data to biomedical research, and like Denise, cited this as a reason for why they had been re-contacted to participate in this study too.

The iterative nature of participation within participants' lives makes it difficult to attach motivations to any individual study or identify a single moment at which participants 'decide' to participate. Becoming involved in longitudinal research can precede the start of the study, as opportunities to participate repeat through participants' lifetimes, and (as Audrey suggests below) indeed beyond the end of life. For these people, research participation is an ongoing and even cyclical process—where becoming a participant is a process of becoming part of the "loop". Nor moreover, does this loop encompass only an individual's study participation; it involves moral and affective processes relating to the lives of participants and their families.

> "Oh, how did I come to take part in it? Well way back, about six years ago I think, I signed into the donating my brain for research... They wanted a number of so-called "normal" brains – that's assuming I haven't died of Alzheimer's – to compare with Alzheimer's brains. I thought about doing it when my brother died which was ten years ago now and I didn't quite feel ready, but after a few years I thought, go for it. So that seemed to get me into the loop for Alzheimer's research."
>
> (Audrey)

Audrey's brother had died of Alzheimer's, along with many members of her family, who have a genetic predisposition to the condition. Her account demonstrates the overlaps between the process of advertising and recruiting for biomedical research (getting people into "the loop for Alzheimer's research") and the lived time of experiencing, coming to terms with, and acting in response to the death of her brother. After genetic testing showed she was one of those who did not carry the same gene, participation afforded her the possibility of putting her "normal brain" to good use. Becoming ready to do this brought her into alignment with the biomedical research agenda, making her a willing participant in the Alzheimer's research "loop".

While family history acted as to create the conditions of possibility for participation, the connection between these histories and individuals' reflections on their own futures and those of "people like me" was also central to discussions about participation. Participants were generally well-aware of the uncertainty surrounding how and whether a risk for late onset Alzheimer's would be passed on, and likelihood that research would progress sufficiently "in time" for them; explaining the focus on "people like me" when discussing treatment benefits, rather than counting on any personal gain:

> "There's also the hope that it will benefit people like me, probably sometime in the future rather than when I can see it. I like the idea. My mother went down with Alzheimer's and at the time they told me that it's not hereditary... probably the upshot is it's one of these things where there are probably genes that make you more susceptible."
>
> (Denise)

The idea of "people like me" connects present practices of research participation to past situations, in which family members were affected by dementia, and to expectations of a potential future in which dementia might be prevented. Decisions to become a participant thus emerged as embedded within temporally extended practices and relationships as well as those that are immediate and current. The ongoing engagement of continual research participation afforded possibilities (and expectations) to connect past, present and future.

Continuity of role: Keeping busy, staying useful

Possibilities for participants often related to the way that participation practices in the 'now' could contribute to a sense of continuity into the future. Lindsay, who was active in one of the EPAD participant panels,[3] spoke about people she had met during the research and how they shared the benefit of hindsight, current access to information, and their outlook on the future:

> "A lot of us have seen friends or family friends or family of friends who have developed dementia... almost all of us [on the participant panel] have said 'I'm not going to go through that.' Well, I think we are pretty much all of the mind that we would like to be prepared so that we can do something about it ourselves. We don't want to end up in that rocking chair."
>
> (Lindsay)

The temporal dimension of the relational aspect of participation is apparent in this participant's relationships prior to the research, compared to those that have emerged and formed during the research. The latter group that she identifies with are those who have decided to take action in ways not open to friends and family in her past. While it remained unclear how this participation would directly prevent one "[ending] up in that rocking chair", this sense of being situated both in a set of relationships, and in time, underpinned an idea of research participation as a form of being or *staying* active.

Regardless of direct benefits of the research to health, the opportunity to 'be active' and 'keep busy' was important to participants as an element of their social and professional lives. For example, for many, research participation was associated with retiring or winding down a lifetime of work. Marion, in her mid-sixties, had stopped her teaching job but still worked full-time in education from home, taking days off to participate. Her words animate a particular 'lived present' that was distinctly connected to "being part of society", but which situates these social relations in relation to her past and possible future:

> "In terms of the Alzheimer's study, I guess, yes, we all have a responsibility to try to ensure that, if not we, that others don't spend 10 or 20 years of their lives as cabbages. I mean, one of the things that makes life worth living is feeling useful, and if you can't give anything, if you can't be a part of society and react to it, then it would be pretty miserable"

The feared future of living passively "as a cabbage" reflects well-documented negative imaginaries of dementia in the face of current expectations to be able-bodied and able-minded in order to age 'successfully' (Sandberg, 2021; Sandberg & Marshall, 2017). This is compared to the present possibility—and indeed responsibility—to be active in preventing this imaginary, for herself and others. Her responsibility to society is thus closely bound up with a very personal sense of what she has valued and continues to value in life. As she goes on:

> "I hope that my participation in the study is going to be useful...But as you get older, you are conscious that what you can give is decreasing"
>
> (Marion)

Marion sets out how the affordances of participation are situated in and shaped by the lived time of participants, as well as by the temporal possibilities of research in connecting and shaping links between past, present and future relations. Marion's participation is a particular way of 'doing' participation that is afforded by both the research and her own personal history. She had explained previously that she had been brought up a strict Protestant and suggested that research participation might be a "post religious thing" in a world where we put our hope in science rather than God. Others' sense of duty to keep busy or stay useful was less clearly religiously grounded, but equally tied to a 'work ethic':

> "...to do something positive because there is this sense of 'what's the point of retirement?' Because it's very difficult when you stop full time work ..."
>
> (Malcolm)

Reflecting the high proportion of university educated participants in the cohort at large, "work" often referred to careers in science, medicine or academia. We spoke to several people for whom participation emerged as a possibility to continue 'doing something useful' for research or medicine:

> "As I said, I was a doctor before, so I was aware trials were going on in branches from general. But, as a GP I didn't, actually, have a huge interest in dementia. But coming up towards my retirement I started thinking about what I was going to do."
>
> (Mick)

Mick here sets out how dementia research is particularly relevant to a certain *stage* in a working life (as well as a corporeal, biological life), but also how participation in this research also creates a sense of *continuity* as people move between stages of life. Research participation creates a space to continue the 'work' of knowledge production at a time when careers come to an end. The trope of *staying useful* (and as we explore more fully below, *staying healthy*) was one way to carry forward the continuity of the past in the face of change in the present and looming threat of the future, of living the 'third age' in the shadow of a personal and social imaginary of the 'fourth age' (cf Higgs & Gilleard, 2017). So, participation affords ways to *continue* certain practices and work at times of flux and change, whether through the 'normal' ageing process or in the accelerated decline associated with dementia.

Continuity of body: The 'incidental benefit' of the "M.O.T"

In addition to continuity of participation and social role, participation affords opportunities for people to have a sense of continuity in their bodies and cognition. During the informed consent process, participants were told that they should not expect individual feedback or test results on a routine basis, so knowing specific details about health, biomarkers or cognitive change was rarely cited as a motivation to participate. However, knowing and feeling that there had been *no change* to speak emerged as an attractive and reliable reason to participate and to continue participating. This valued state of continuity ('no change') came from a combination of a personal sense of having 'done well' on cognitive tests and a 'no news is good news' logic on the physical ones.[4]

In interviews, the check-up emerged as "a benefit that I wasn't really expecting" (Elizabeth), or "a few more goodies, that I might have" after signing up (Gordon). This kind of emergent benefit was often described jokily as "the M.O.T."—a functional check-up where you would be alerted to any (actionable) problems or given the 'all-clear' without needing to know experimental neuropsychological test scores or the inner mechanics of what was going on in the body:

> "I looked on all these tests as getting a free M.O.T., they were checking everything and they found a couple of things, which as they said at the beginning, if you find anything, they report it to your GP – they don't deal with it here"
>
> (Sheila)

Another participant found that in the course of the study she would become ineligible for the NHS five-year health check, because she was getting to "the wrong age," as she put it. Moving onto a new life stage (above 75), the check-up she got from taking part in the research *became* beneficial in lieu of the NHS check she could no longer access. These informal and implicit forms of feedback, which emphasise continuity (and health) rather than change (and illness) might be considered 'incidental benefits'—comparable to the notion of 'incidental findings' (Wolf et al., 2008). These incidental benefits were often discussed as a positive and compelling aspect of continued participation. Monitoring a lack of change in (brain) health in this way was important to many of these older adults, who understood they may potentially develop 'silent' symptoms, as we described in the introduction.

Given the lack of treatment options for being biologically 'at risk' for Alzheimer's, there was very little consensus amongst participants about whether they would want to know biomarker results were they to be routinely made available in the study. But the M.O.T had widespread appeal because it could generate a more general sense of being cared for over time. Regular testing was a way of being "kept an eye on" (in the words of one participant) and created opportunities for care, albeit non-therapeutic. In this way, many participants found the clinical attentiveness of the study team reassuring or even pleasurable, even if there was no longer term treatment or benefit directly associated with it:

> "I mean, it is quite nice knowing that you've been checked over even though obviously they might find something that perhaps you didn't know about and you perhaps didn't want to know about but, you know, it's nice. It was more— I just like the attention. I like going to the doctor and I like going to the dentist."
>
> (Claire)

Crucially, the M.O.T. was something that emerged during the research process and came to be seen as almost immediately useful. During participation in the longitudinal cohort study, a base level of 'being OK' was established, even if participants knew there may be other changes in biomarker levels and neuropsychiatric scores that were not being disclosed. As we discuss below, however, there was a potential for these research conditions to change with the possible introduction of a drug trial—in terms of greater possibilities for finding out one's biomarker status, and the potential future treatment benefits, were the trial to be successful.

Anticipation

In this part, we consider how the future-oriented dimensions of participation produce evolving affordances of observational and clinical trial research. Specifically, we draw on the unique structure of the project to consider the relationship between present and future participation. We consider participants' outlook on the possibility of taking part in *future* clinical drug trials. At the time of interviewing, these had not been launched and remained an abstract possibility for future involvement in the project. However, all participants entering the study had been asked to consent to being contacted for such trials. Considering clinical trial participation required participants to imagine how their future decisions and practices would unfold as the research process changed and their own bodies and lives changed. We therefore focus on the changing affordances of clinical research via three perspectives on anticipated futures: participating in possible futures, unfolding futures and therapeutic affordances.

Participating in possible futures

At the time of interviewing participants, the longitudinal cohort study was approaching the stage where the first pharmaceutical drug trial was due to start. Expectations for future participation required a different set of considerations about what experiences and possible risks and benefits this practice might involve. Whereas the perspectives described above emphasised the ways in which participation in EPAD afforded a sense of continuity within people's social and biological lives, the future-oriented design of the study required participants to think about their involvement in the study in the context of changes in self, body and brain, imagined along a singular, biomedically defined trajectory.

In their discussions of participation, the majority of participants did not talk about gaining access to future treatments; as we have mentioned above, participants generally had a clear understanding that they were unlikely to gain treatment benefits from the study. However, participants did describe futures in which the possibility of a preventative treatment might *become* attractive:

> "... I mean, I think if something like that happened and either of us had some symptoms and this was a possibility of counteracting those symptoms, then we would welcome that. But the purpose in jumping into the research was, in a way, much more altruistic, if you like, than personal gain, in that kind of way."
>
> (Nigel)

The shifting ways in which Nigel speaks about why he participates—and has continued to participate—as well as whom it might benefit, brings into focus the shifting needs and interests at different moments in time. While he describes the initial purpose of "jumping in" as altruistic, when Nigel imagines a future in which he or his wife (also an EPAD participant) developed symptoms of dementia, he imagines they might welcome the possibility of personal benefits.

Others, like Gordon, were less concerned with their own trajectories and were more concerned with participating in the kinds of "breakthroughs" offered up in possible biomedical futures. Below, he discusses his experience of attending a conference for participants organised by the study:

> "I have every confidence that we will crack this, and the conference just really supported this fusion now of data scientists, data science and clinicians... I just think it's so exciting and we will be making breakthroughs."
>
> (Gordon)

Overall, however, while the research study offered up possible futures, it did not dictate how people thought about ageing and their chances of developing dementia. When asked whether taking part in the study changed the way they thought about their own future, people tended to refer to existing and ongoing imaginings of the future, that research participation touched upon but did not radically change. In this way, participants' existing experiences and expectations of ageing shaped how they engaged with research and imagined the possible futures it might produce.

Unfolding futures

The way in which participants imagined their futures, and their expectations for trial participation depended on the kind of possibilities and hopes available to them, and the needs they

anticipated. While the material above describes how participants imagined possible (more distant) futures, others described their futures as they unfolded from the present.

Christine, for example, lived alone and had only one family member; a brother who lived with multiple sclerosis (which, like Alzheimer's disease, is neurodegenerative). In contrast with the narratives of continuity above, due to her particular circumstances, Christine was keen to anticipate and prepare for change—a future where she developed dementia—by doing everything she could do gain access to care and potential future treatments. While she was no less aware than other participants that treatment benefits were unlikely, she was more motivated by the threat of change and the *possible* benefits of the trial than others whose imagined futures emerged from less precarious presents:

> "It's almost a little – selfish is probably the wrong word... I'm thinking about my future, and, you know, how I... how best I can be looked after or look after myself at a stage when I would need, sort of, third party help... if I'm part of this exercise, this study, then going forward I still might be able to join other studies at a later time as I get older - Perhaps even if I start to feel that I'm getting more forgetful than we normally are, or normally can be. So, I'm hoping it just paves the way for perhaps future studies and help. Really that was my reason for joining this study at this stage, at this time."
>
> (Christine)

Although fairly atypical of this cohort (as a single woman with less financial security), Christine was not the only participant to express concerns about the need to anticipate an uncertain and discontinuous future due to having a family history of dementia, paired with limited options or finances for future care. A key message was that the possibilities and limitations associated with people's imagined futures emerge very differently as research is situated within biological *and* social lives. While a straightforward 'cure' for dementia was almost never an expectation of this piece of research, participants engaged with *possible* innovations and breakthroughs that could affect the course of conditions associated with ageing. The hope that participation "paves the way" to infrastructures of (potential) new therapeutics and care, which Christine could see emerging from projects like EPAD, is an important example of participants assessing what research might afford themselves and/or society, and how this might fluctuate at as certain futures unfold.

Therapeutic affordances

Within these unfolding futures, some people suggested different ways they might engage with the research, thinking about how the problem might be delayed (with a preventative treatment or more general brain health activities) or play out differently (with new opportunities for care or experimental treatments). This moves us away from the notion of 'therapeutic misconception' (Appelbaum et al., 1987), which focusses on individual knowledge and beliefs at any given time, rather than this dynamic engagement with what a future treatment might become to them. Others mentioned more unexpected ways in which they hoped the research may be beneficial, such as enabling one participant to work on specific neuro-cognitive functions through meditative practice. Another participant imagined alternative non-pharmaceutical treatments that she would more comfortably engage with, such as aromatherapy, which again, built on existing practices of maintaining (brain) health.

In this way, these data suggest that the concept of 'therapeutic promise' (Rubin, 2008), could be refined and extended in the context of on-the-ground practices, (as opposed to broader scientific discourse) to acknowledge how biomedical innovation *interacts* with different ageing lives and expectations of continuity and rupture. We propose the concept of 'therapeutic *affordance*' as a means of capturing and understanding these expectations, hopes, concerns and intentions for future biomedical research participation.

DISCUSSION

Through these accounts of research participation, we have traced the evolving practices of research participation through the course of a longitudinal study for the prevention of Alzheimer's dementia. Specifically, we have explored the way the temporalities of research and everyday life intersect and how participating, and continuing to participate, in dementia prevention research becomes an "everyday act" of world building (cf Dokumaci, 2020, S97) that affords opportunities to establish continuity and anticipate change.

Our analysis suggests that participation is a relational achievement, as captured in existing work on participation (Dove et al., 2017), but also distinctly temporal, as everyday life and biomedical research intersect to shape moments and trajectories of participation and its possibilities. This way of understanding participation amid temporally situated relations offers the possibility of building on the work of Mwale (2020) and others to draw out important observations about how the practice of research participation is differently situated in time. In particular, our effort to capture the dynamic interplay between what research might (or might not) offer at specific points in research participants' lives, and how these lives create the possibilities for research extends beyond ideas about singular motivations for participation, and indeed single research studies. It demonstrates that people's reasons for (continued) participation are emergent and contingent on the multiple timelines of ageing and research. Rather than understanding these timelines of everyday life and research participation as separate temporal 'tracks', we instead observe how biology, history and culture are "inextricably entangled" (Chilibeck et al., 2011, p. 1769), meaning practices and imaginaries of ageing and those of knowledge production in dementia cannot meaningfully be teased apart.

To extend our analysis of the possibilities associated with these situations, we here draw on work on affordances, particularly as elaborated in the recent work of Arseli Dokumaci (Dokumaci, 2014, 2017, 2020), and previously by Ingold (2000) and Gibson (1976/2014). In her work on chronic illness and disability, Dokumaci describes affordances as relationally constituted interactions between and individual and her environment, whereby the timing of activities and movements is attuned to specific situation of opportunity or 'readiness' (Ingold, 2018, p. 397). For Michael, "affordance thus lies at the 'interface'—or better, the concrescence - of the individual's bodily capacities, her unfolding plans, and the propensities of the object" (Michael, 2016, p. 652). A processual focus on these concrescences and interfaces between capacities, objects and plans shows how possibilities and limits of living arise not only in relation but in time, coming together and extending into the future. For example, through the ways disabled people might invent "accessible futures" where the present environment fails them (Dokumaci, 2020, s100). This leads us to consider the potential of research participation as situated in, and emerging through, relations to the intersecting timelines of research, innovation and everyday life. The 'object' in this concrescence is the longitudinal research study and its evolving possibilities and limits for research participants. As we have shown, these possibilities emerge through their

intersection with the experiences, capacities and plans of participating individuals. Responding to the dominant focus on static motivations and decision-making processes in clinical research participation, our use of affordances goes further in engaging with the temporal and relational aspects of the 'problem of participation'.

The extended and overlapping temporalities we describe contribute to differing limits and possibilities for care and agency, which we describe in terms of affordances (Dokumaci, 2017; Gibson, 2014; Ingold, 2000). The focus on ongoing practices of research participation comes with a sense of continuity: it enables "staying" useful, "keeping" busy and contributing to science whilst "still ok". In that sense, for our respondents the possibilities of research afford a particular kind of aging, "assimilated" into the figure of the active and productive aging citizen, in the face of the 'monstrous' spectre of dementia (cf Latimer, 2018). This reflects the possibilities of what Van Dyk dubs "Happy Gerontology", which stresses the "continuities between midlife and independent/active later life" (2014, p. 93). The possibilities for 'successful ageing' here are, however, bounded and participants were also acutely aware of the *limits* of what research can afford. Specifically, that there is currently little that can be 'done' to prevent the possibility of developing symptomatic dementia; something that "loomed" ever larger, in the words of one participant.

Knowing there was little or no effective medical action associated with learning about early biological signs of dementia risk, participants nevertheless highlighted the possibilities research afforded for care (such as "being kept an eye on"). Previous research has shown that the lack of formal clinical care within the research protocol does not foreclose possibilities for care to emerge within research practices (Fisher, 2006; Wadmann & Hoeyer, 2014). What we demonstrate is that these affordances for care emerge at particular points in the research process and can be seen as 'incidental', in that they are related to the concerns of being a certain age and the current (lack of) possibilities offered by biomedicine. This opens up a different perspective on the "reshuffling of the research/care distinction" that social scientists have been observing in areas where more viable treatments are already in use (Cambrosio et al., 2018, p. 207).

The affordances of participation become particularly interesting as they are considered in terms of how a future experimental drug trial fits into participants' experience of their own and others' aging and their anticipated futures. This was not only contingent on hopes for a new treatment to slow or halt cognitive decline, but also participants' own outlook: how they would feel if they were to develop symptoms, their future social and familial situation (e.g. not having children to support them), as well as concerns about wider society (i.e. the 'the ageing society'). Our conceptualisation of participation through the temporalities of research and the life-course highlights the intersections and *interactions* between lived futures and the promissory biomedical futures (cf Pickersgill et al., 2015; Rubin, 2008) to which participants were exposed, which in turn create an anticipation of future affordances. Our concept of therapeutic affordance builds on that of therapeutic promise (Rubin, 2008) by foregrounding the specificities of lived time, and specifically lived futures, in relation to possible treatments.

Our study and findings are limited by the extent to which we were able to explore research temporalities in practice - we only interviewed each participant once within the context of a single study, albeit at a range of moments in the research process. Our approach in this sense followed the example of much sociological investigation undertaken in the context of specific biomedical research studies. To develop our findings and extend investigation, further research would usefully follow participants over time, through the multiple research contexts that intersect with individuals' everyday lives. Critically, such work would shed light not only on how affordances of research practices emerge at the intersection with the lives of certain 'kinds of person' but also how the absence of such intersections limits both the opportunities and affordances for others.

In this article, we have aimed to open up a conceptual space to explore people's iterative and ongoing engagements with research and technologies throughout the life course. Specifically, we suggest that attending to the affordances of participation offers a productive mode of thinking about why, how, and critically, *when* research participation happens, as it emerges in relation to, and interaction with, the lived times of ageing and everyday life.

ACKNOWLEDGEMENTS

We are grateful for the contributions and assistance of the EPAD researchers at participating centres, and to the participants who made this study possible. Thanks also to the Scottish EPAD Participant Panel for their input on the design and implementation of the study. This work was funded through EPAD which receives support from the Innovative Medicines Initiative Joint Undertaking under grant agreement no. 115736, resources of which are composed of financial contribution from the European Union's Seventh Framework Programme (FP7/2007-2013) and EFPIA companies' in-kind contribution. RM's contribution is also funded by the Wellcome Trust under grant 206194.

AUTHOR CONTRIBUTION

Natassia Brenman: Conceptualization (equal); Data curation (lead); Formal analysis (lead); Funding acquisition (supporting); Investigation (lead); Methodology (equal); Project administration (lead); Resources (supporting); Software (equal); Supervision (supporting); Validation (equal); Visualization (equal); Writing-original draft (lead); Writing-review & editing (supporting). **Richard Milne:** Conceptualization (equal); Data curation (supporting); Formal analysis (supporting); Funding acquisition (lead); Investigation (supporting); Methodology (equal); Project administration (supporting); Resources (lead); Software (equal); Supervision (lead); Validation (equal); Visualization (equal); Writing-original draft (supporting); Writing-review & editing (lead).

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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ENDNOTES

[1] Study visits were usually between 6 months and 2 years into the longitudinal study, whilst researchers had been working on the study for up to 5 years and were preparing for a future clinical trial.

[2] One participant we discuss in this article came through a clinical pathway, but this was due to a neurological issue and not a memory complaint.

[3] The EPAD participant panels represent the participant voice for the different countries involved in the study (in this case England or Scotland)

[4] Test results were not routinely given to participants unless there was cause for clinical concern, and the possibility of clinical action. For example, if the cognitive scores had declined to a point where the participant would be diagnosed with Mild Cognitive Impairment (MCI) or there was an 'incidental finding' such as a deficiency found in the blood or an abnormality on the brain that the participant's doctor should be told about.

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How to cite this article: Brenman, N., & Milne, R. Lived time and the affordances of clinical research participation. *Sociology of Health & Illness*. 2021;00:1–18. https://doi.org/10.1111/1467-9566.13374