Three years ago I wrote a brief review of Public and Patient Involvement (PPI) in health research (Ashton 2017). Here, I take a closer look at research on ageing and dementia, through three interviews with people with extensive relevant experience: from the viewpoint of a researcher; a public contributor; and a PPI lead in the Research Design Service.

First interview: Clare Aldus, Fellow of Norwich Medical School at the University of East Anglia:

1) To give some background, describe briefly your role in CADDY – (Undiagnosed Dementia in Primary Care: A Record Linkage Study**,** Aldus et al, 2020)

CADDY was a study to determine whether people with dementia had a formal diagnosis of dementia in their primary care record. I was not involved in the initial design of the CADDY study but was employed to work as study manager. The role of a study manager is to carry out the day to day management of the study under the direction of the Principal Investigator. It involves a diverse range of tasks such as conducting research, collating data, working closely with PPI and problem solving to name but a few. In CADDY I had the privilege of working with an advisory group of ten PPI members who had experience or involvement in care of people with dementia. Their contribution was invaluable in the design of the analysis and interpretation of the findings.

2) As PPI representation has grown over the years, there are now many older people involved in research…

This is very welcome. If we are to conduct research which is meaningful to patients and carers then it is essential that their voice is heard. As a researcher interested particularly in the health of older people my experience is largely with older PPI members. CADDY PPI members were drawn from a local network of people who work with the University on research studies called PPiRes. (Norfolk & Suffolk Public and Patient Involvement in Research Group) *Many of the people who are registered with PPIRes are people who are retired or do not have conventional employment patterns. This means that PPIRes has many older members.*

3) However, the older generation may be deterred by, for example, feeling out of step with technology, or not having the same powers of concentration as they used to.

This is a valuable point and those concerns may be felt quite keenly but it is a key responsibility of the research team to ensure that appropriate steps are taken to support all members of the team whether young or old. The researcher should try to capture the needs of the PPI members of their team. For example do they like to use email or would they prefer a letter? In face to face meetings the facilitator needs to make the attendees feel relaxed, that their voice is important and contributions valued and it is important to be inclusive without making the PPI member feel as though they have been 'put on the spot'. It is difficult to meet all the diverse needs of PPI groups on every occasion but it is important to keep trying.

4) Do you think the typical profile of contributors means that representation is not very representative?

In my experience PPI representation has been representative. We were not able to include people with advanced dementia in the discussion groups but we did include older people who care for people with dementia. We held a large dissemination event at the end of the study, to increase the impact and visibility of the study, and arranged for a talk by a gentleman who has dementia. His talk was very emotive and the best received of all. We had costed well for PPI and were able to provide the necessary support for travel and accommodation for him and his partner as well as other PPI members to attend the event.

5) PPI often takes the form of having one or two contributors attending meetings, and more or less integrated in a project. Do you think other formats should be employed, such as consulting a larger panel more frequently?

In the past I have been involved in studies that have a small number of PPI members as part of the team and their contribution has been valuable and very positive. However, having worked on

CADDY which ‘employed’ a 10-person advisory group I now feel that a much larger group confers huge value. They provide a much broader picture of the problem and potential causes, often prompted by simply talking to each other and sharing experiences. In the future I will aim for a broad advisory group from which we will select a small number of volunteers to contribute to management and steering group activity.

6) In research on ageing, and particularly dementia, what do think are the best ways to involve people?

In my experience longer meetings of at least two hours with some tea and biscuits means that there is sufficient time to meet and greet, to explain the issues that are to be addressed with any ‘training’ that is needed and also to fit in two meaningful discussions around specific issues.
The personal experience of older people and people with dementia provides a powerful tool which can help the team to achieve impact, and so inclusion in meetings with policy makers and commissioners can be very effective.

7) In planning research, do you think there is often an under-estimate of the cost of PPI, both in terms of time, and financially?
If so, how could this be addressed?
I think the problem is more one of understanding the value and cost of PPI in research. Funders seem keen to include PPI in research and in my experience provide the requested funds. However, if researchers do not plan enough PPI into a study then it cannot be adequately costed. Researchers must be bold: Healthcare research is for patients and carers.

8) Would you like to make any comment on the current development of PPI, and perhaps future direction?
I am an older researcher. During my working life I have seen PPI go from zero consideration and zero support to absolutely essential in every way. Things can only get better.

Second interview is with Peter Richmond, public contributor in Norfolk:

1) You were a member of the team lead by Luke Emrich-Mills (Emrich-Mills et al, 2019) , collecting a lot of information on priorities for research in dementia. Can you briefly describe the project, and your role? Were you able to take as active a part in the research as you expected?

*I became aware of the proposal to do a local study into research priorities for dementia when I received an email in January 2017 from Research Assistant Psychologist, Laura Hammond, asking if I would help with a discussion to develop the idea. Following approval of the project by the NSFT (*Norfolk and Suffolk NHS Foundation Trust*) Research Committee, both I and second lay representative, Kate Massey, met regularly over the next few months to help develop various survey documents which were intended to form the basis of a final consensus meeting in September 2017. But organization of such a large meeting before the end of the time available proved a task too far and the project remined uncompleted. However, in December 2017 Luke Emrich-Mills, newly arrived with NSFT, agreed to take up the project lead. Sadly at this point Kate, who had contributed so much, died.*
We were fortunate to be joined by Juni West, Research Development Lead, Older People’s Services, Norfolk and Suffolk NHS Foundation Trust and over the next few months Luke, Juni and myself met a number of times and evolved a more structured list of over 100 potential research questions relevant to both clinical staff and service users. At this point we sought to contact the wider community of staff and lay people – in fact anyone who had thoughts on the matter - Church communities, charities and random associates with pertinent experience, were all invited to comment on the questions and offer their ideas about ranking.

2) How much difference did your contribution make to the study?
Armed with this revised list, the project then culminated in a one-day meeting facilitated by Luke on November 27th 2018 with around 20 or so clinical staff, service users and people with dementia. During the day, Tom Rhodes and Juniper West, both from NSFT, and myself facilitated

discussion within a series of three subgroups. Each subgroup of four participants included a clinical psychologist or nurse, a person with dementia and a care worker or spouse. The role of the chair was crucial in the sense that it was important to be neutral and encourage all the different voices in the group to contribute. The groups were rotated after lunch. And so, by mid-afternoon using all the input from the subgroups Luke assembled a final ranking. What proved interesting was how the final ranking revealed just how extensive the consensus on the day proved to be.

It was no surprise that the projects focussed on practical rather than theoretical objectives and many but not all the topics were similar to a list recently published by the Alzheimer's society. Details of the study were later published. (ibid, 2019)

*In one sense, engaging in this kind of process was very familiar to me; what was different was being a lay person in the group. My reward was greater understanding of the many problems faced by those with dementia, their carers, and clinical staff when confronted by these issues. Having had lengthy experience of both general and research management during my career albeit not in medical science, engaging in this kind of process was very familiar to me; what was different was being a lay person in such the group. Having been involved both in CADDY, the RfPB (*Research for Patient Benefit*) grant committee and now this project, my reward has been much greater insight and understanding of the many difficult problems faced by patients, carers, and clinical staff.*

3) As PPI representation has grown over the years, there are now many who could be described as expert public members. Do you think this means they are no longer represent the general population?

I doubt PPI representatives will ever be fully representative of the general population, many of whom have never, thank goodness, experienced serious health issues either directly or indirectly. Equally no one person has experience of every health issue; what is important is that as a group on a committee they are able to assess projects in a number of areas: cancer, heart issues, psychological problems, etc from either a patient or carer perspective. Some concerns are common to many areas of course. Being a carer or family member has its own problems whatever the nature of the illness.

4) Do you think NIHR (National Institute for Health Research) procedures regarding public involvement could be improved?

In my view, the NIHR works well, however there remain areas, such as suicide and drug addcition, to name but two, where securing suitable members willing to participate in committees can be difficult. This can limit adequate assessment of proposals targeting these problems. It also does not help the research community, either with feedback on their proposals or, if they are rejected, to build research capacity in these areas.

At present, all proposals considered by the committee are submitted directly or in response to a special call. Either route is, in effect, a bottom up response to the committee. Other research councils have in the past used more directed approaches to build activity in certain priority topics. Here an expert in the area is appointed, provided with a budget and told to establish a research programme in his special area. He may use a subgroup of expert advisers but in effect he is a quasi-dictator charged to get the programme off the ground. I see no reason why this model could not be used by NIHR in difficult areas. Mental health might be one such route.

5) The older generation may be deterred by, for example, feeling out of step with technology, or not having the same powers of concentration as they used to. Do you think this means that representation is not very representative?

Although it there is concern about older people who have not taken up new technology, the majority of those I know do use technology for many tasks including communicating with friends and family, as well as general interests. The recent pandemic has no doubt caused more and more to gravitate to using computers and mobile phones. Within a few years their use will be common place in all age groups.

6) Do you think that PPI members of research projects are suitably rewarded for their time and commitment?
Lay members who attend meetings or spend time reviewing projects are rewarded for their time. Lay members are also reimbursed for direct expenses. This is perfectly adequate in my view. Financial reward is not, in my opinion, the reason lay people volunteer to serve in this way.

Third interview is with Helen Allen,
Research Design Advisor and Public and Patient Involvement (PPI) Lead, Bournemouth University Clinical Research Unit :

1) To give some background, describe briefly your role.

I am a qualitative researcher by background, based at the Bournemouth University Clinical Research Unit. As PPI lead and research design advisor, my role is part funded by Bournemouth University and part funded by the NIHR Research Design Service (RDS). Our main remit is to support academic colleagues and healthcare professionals from the surrounding Trusts in applying for peer reviewed national funding, often NIHR funding streams and national charities. My role is to facilitate and encourage timely and appropriate PPI, ideally from the outset, during the grant application process, following through to post award, during project delivery and during dissemination activities.

2) As PPI representation has grown over the years, there are now many older people involved in research. However, the older generation may be deterred by, for example, feeling out of step with technology, or not having the same powers of concentration as they used to. Do you think this means that representation is not very representative?
I think it is more down to individual differences than that. Some older people are just as familiar with technology as younger, and just as sharp cognitively. On the other hand, some younger people are not very IT savvy. Thus we need to be aware of popular stereotypes when engaging with people by virtue of their age. If we are working with people who are cognitively impaired, there are a variety of methods which can be used to help with this eg interactive workshops, breaking tasks up, etc.
It's important to note that PPI groups are not necessarily representative of the group which the main study is about, but they could be carers, spouses, family, members of relevant support groups or national organisations, so not representative as such but having a vested interest in the project.

3) PPI often takes the form of having one or two contributors attending meetings, and more or less integrated in a project. Do you think other formats should be employed, such as consulting a larger panel more frequently?

We think of our PPI work as a sort of smorgasbord of opportunities for the research team to interact with our advisors. The decision about whether it will be group, or individual work, face to face (COVID-19 notwithstanding) or remote, online, etc. is determined by the nature of the project, what the advisors are being consulted about, what the team think is appropriate, etc. We have used a national online panel before when there was no-one appropriate available locally but a pre-existing national group was keen to support us. Pre - COVID, small group meetings were common, but we also have done PPI work over the phone and even in service users' homes where they expressed a preference. The prime consideration is how advisors want to work with us: some like small group work, others are intimidated by the idea of groups and want to work on an individual basis.
It is also relevant whether a discussion of several people would inform the project better, or differently, than consulting a smaller number, perhaps in more depth. I think the decision re which PPI method is most suitable needs to be a consideration of the project requirements and the wishes of the older persons being consulted, and an exploration of where the two can overlap for maximum benefit to both.

4) In research on ageing, and particularly dementia, what do think are the best ways to involve people?
Again, the best ways to involve people depend on the project and how the people like to be involved. There isn't a one-size fits all! At Bournemouth University we have an Ageing and Dementia Research Centre so we have plenty of in-house experts as well as our previous work to inform us. There may also be pre-existing PPI groups. As before, it also depends on the exact nature of the project, what is required of the advisors, what they feel able to contribute, and how they would prefer to work eg small group or individual 1:1 sessions. (see also Q3)
In our Tai Chi project we had a 4 People With Dementia (PWD), 5 spouses of PWD and a daughter of a PWD. (Nyman et al 2018)
These 10 individuals provided input to the development of the trial protocol, and continued to provide PPI input throughout the trial at regular intervals.

5) In planning research, do you think there is often an under-estimate of the cost of PPI, both in terms of time, and financially?
I think if the research team have early access to those in a position to help, in our case the Research Design Service South West, and are signposted to the correct resources, there should not be an underestimate of costs. The NIHR INVOLVE website has many resources including a step by step guide to planning costs. (NIHR 2014)
The amount of time needed for PPI can be underestimated in terms of relationship building and getting things set up for an advisor consultation. We advise as a minimum to allow for 6 weeks, and longer during the current pandemic. Again, early engagement with our team can mean timelines and deadlines can be discussed at the outset.

6) Would you like to make any comment on the current development of PPI, and perhaps future direction?
Engagement work is becoming more popular and can serve as a useful link between what the university is doing already and what the local community might feel they wish to be involved in. In this way each university has a defined medium through which research can be promoted to its local community, and the public can have a say in what matters to them.

Reference List:

Aldus, C.F.; Arthur, A; Dennington-Price, A; Millac, P; Richmond, P.; Dening, T Fox, C.; Matthews, F.E.; Robinson, L.; Stephan, Blossom C.M.; Brayne, C.; Savva, G.M. (2020) *Undiagnosed dementia in primary care: a record linkage study* Health Services and Delivery Research. 8(20), 1-108.

Ashton, J. (2017), *Public involvement in public health research*, Journal of Public Mental Health, Vol. 16 No. 3, pp. 123-126.

Emrich-Mills, L., Hammond, L.L., Rivett, E., Rhodes, T., Richmond, P. and West, J. (2019), *Identifying research priorities for older people's mental health services,* Mental Health and Social Inclusion, Vol. 23 No. 2, pp. 89-100.

Nyman, S.R., Hayward, C., Ingram, W.; Thomas, P., Thomas, S., Vassallo, M., Raftery, J. and Allen, H. & Barado-Martin, Y., (2018) *A randomised controlled trial comparing the effectiveness of tai chi alongside usual care with usual care alone on the postural balance of community-dwelling people with dementia: protocol for the TACIT trial (TAi ChI for people with demenTia)* BMC Geriatrics, 18:263

NIHR (National Institute for Health Research) (2014) https://www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/involvement-cost-calculator/ (accessed 12.06.20)