HARG seminar presentation - 6th Oct 2020

**Co-production and added value inresearch with older people**

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***ABSTRACT (for info here only)****:Our research seeks to understand the pressures, dilemmas and practical difficulties experienced by older people who have to organise and pay for their own care services.Thethree-year study,Ethical issues in Self-funded Care, supported by the Welcome Trustis a collaboration between the universities of Lincoln, Brighton and Birmingham.*

*The researchis taking an innovative approach by working closely with groups of older people in each site throughout the project. The input of these co-researchers extends beyond their involvement in field work and data gathering - arguably the most common aspect of research available to lay participants.*

*Instead, Co-researchers in Brighton were instrumental in conceptualising the research and in Lincolnshire in addition to the fieldwork, Co-researchers undertook the development and application of coding schemes and completed much of the initial thematic analysisas well as attempting more complex narrative analyses. This experience has beenboth exciting and enriching for individuals in the group. As the project reaches its conclusion, the Co-researchers have enthusiastically taken up the latestchallenges of online dissemination.*

*A further innovation was having an independent evaluation of the participatory aspects of the research embedded in the project from the start. The three site-based groups of co-researchers and academics have been encouraged to reflect on their experiences of the research and this presentation will focus on the added value that the Co-researchers participation has brought to the project and considers some of the obstacles and limitations that we experienced as a research team.*

**I’m assuming some welcome and introductions to be done by Mo/Tom.**

Phoebe:

Today we’re going to talk about our three-year study *‘Ethical issues in Self-funded Care for older people’,* which isfunded by the Welcome Trust and is a collaboration between the universities of Lincoln, Brighton& Hove and Birmingham.

Our research seeks to understand the pressures, dilemmas and practical difficulties experienced by older people who have to organise and pay for their own care services.

I joined the team at the end of last year, after the project had been going for some 2 and half years, and part of what attracted me to the post was the innovative and participatory approach to working with groups of lay Co-researchers and a community partner organisation in each site.

We have been given a short extension to the project, until January, to undertake a Covid ‘Postscript’ review of how the pandemic has affected self-funders.

In Lincolnshire, our co-researcher group consists of nine older people from across the county with diverse professional backgrounds, and a representative from a community-based Charitable Trust serving the needs of older people in Lincolnshire.

This group of co-researchers has been invaluable to the project, not only in undertaking in data gathering activities – mapping the local scene, finding participants, doing interviews - but more unusually perhaps, in contributing their perspectives to the analysis and becoming involved in dissemination activities such as this.

In the same spirit of co-production, Tony Gaskell one of our co-researchers is with me today. He has been involved in this research project from the very beginning so has a wealth of knowledge and I’m going to begin by asking him some questions about his experience of the project, and then we’ll turn the tables and he can quiz me.

So to begin with….

**Could you explainbriefly how you got involved, what interested you in becoming a Co-researcher on this Projectand how has your interest been sustained?**

Tony:

My involvement in the project stemmed from my attendance at a University of Lincoln Partnership and Stakeholder Event entitled “Excellent Ageing” in January 2017. My interest was both vocational and understood as an opportunity to renew or consolidate previous experience of Higher Education at Postgraduate level several years ago.

In the early stages of the project we were also introduced to the wider PEARL initiative [ Public Engagement for all in Research at Lincoln ] and the School of Health and Social Care ‘Together’engagement programme within the College of Social Science.

The Wellcome Trust funding secured recruitment of anAcademic Research Fellow which directly involved the Co-researchers at the recruitment interviews for this post. Subsequently, we’ve worked alongside Professor Mo Raywho presented at HARG last week in the first of these Autumn Seminars.

Phoebe: **What activities have you taken part in over course of the project ?**

Tony:

Most of the research related activities have been co-produced and jointly engaged in and we meet regularly, and now online. Other elements of the analysis have required individual work, including our participation in the evaluation.

Our activities have included:

* A joint collaborate review of regional data and information addressing the ageing population in Lincolnshire, Dementia levels, home care support, residential and nursing care and unpaid care; We also tried to scope the ease of finding and accessing information about how a person might locate and fund social care in Lincolnshire including the rural dimension. This was prepared as a Report identifying District Councils , Local Authority Hospital Trust websites, Local Community sources of information including the Charitable or Third Sector, Providers and the Lincolnshire Care Services Directory;
* The co-researchers collectively worked on designing questions for semi-structured interviews with the academic coordinators.
* Subsequently there was a joint undertaking to be engaged in face interviews with Older People, focus groups with unpaid Carers [or people who had helped to arrange care for an older person], and thirdly, with Stakeholders which included Local Authority Managers, Commissioners, Social Workers and Third Sector Agencies. This gave us a 360 degree perspective on the experience of self-funders.
* We have contributed to data analysis of the transcribed interviews and the development of **Code Books** drawing out themes and sub-codes – for example Type and Quality of Care , Advantages and Disadvantages of Self-funded Care; The Built Environment and Use of Technology; Finding and securing Care; Complaining about Care.

**Stakeholder Codes** included Organisational Priorities and Organisational Challenges, Key roles and Responsibilities; Level of Involvement with People Who Self-fund Care; and Growth in the unregulated sector – the potential risks.

* A further strand of the research project focused on planning, attending and delivering six Knowledge Exchange Events held over 3 years.; These have involved small group discussions with a wide range of participants discussing particular challenges, summarising and feedback.The last KE6 was achieved online.
* Some of the self-directed work has included literature searches or reading published material on the Care Sector;
* We have been identifying and developing outputs from the project; including

two booklets on the process of finding and funding care were produced, and this was a cross site and collaborative approach which was, in and of itself, a form of comparative knowledge sharing between the 3 HE Institutions.

3. **To what extent has the organisation and delivery of the research required additional training in research methods or reading academic literature ?**

This has been via group discussion and “working through” the research questions and analysis at the Co-research Meetings; The Co-researchers have been proactive in exploring research methodology issues and concerns. At the same time we were also provided with published academic material to read on wider definitions and concepts in the field of Welfare and Care Ethics. Each co-researcher came to the Project with their own experience and stock of lay or vocational knowledge. We have a retired IT professional, a former teacher, various health- and care related professionals, and a former lorry driver among the group. In in the process they have been empowered to personally develop, learn new things, utilise different skills and positively contribute to the research enterprise.

Phoebe:

**This project is an example of Co-production in Social Science , could you explain your understanding and experience of this and how you feel it adds value to the process of gathering data and developing research knowledge.**

Tony:

Co-production is a term which has quite wide circulation in everyday language contexts but it is more frequently brought for attention in the Health and Care Arena- for example in relation to Patient and Public Participation for the Quality Assurance monitoring of Health Service Improvement.

At the outset of the University of Lincoln Research Project, we were initially encouraged to submit personal profiles to the School of Health and Social Care and at the first meeting of the Co-researchers , there was an open and relaxed environment which encouraged full participation and sharing of ideas. Beyond this and at subsequent meetings, the principle of Co-production was thoroughly embedded in all aspects of the development and progress of the Project.

Individual contributions at the meetings have formed part of a collective approach and allowed for flexible decision-making which has thereby continuously informed the research strategy , methods and techniques to be implemented . This has always been inclusive of all participants and sensitively managed by the academic co-ordinators to enable everyone to make a personal contribution in an atmosphere of learning and mutual respect.

The Co-production has also been part of wider collaboration in so far as we have liaised and met with staff from the other two sites at Birmingham Solihull and with Brighton University. This has focused for example, on the joint efforts to produce a Booklet for older people across the three HE Institutions. As part of this there has been a sharing of information and analysis whilst additionally creating the space for specialisation or a division of labour between the Universities.

In unpicking some of the principles of Co-production in more detail, it is possible to identify several principles :

**Sharing of Power; Including all perspectives and skills; Respecting and valuing the knowledge of all those working together on the research; Reciprocity and maintaining and building relationships;**

**Tony: From the academic perspective, what do you think the co-production has added?**

Phoebe:

The group of older co-researchers who have been contributing to this research on self-funded care havebrought a wealth of local knowledge and lived experience into the process of developing the interviews and then sieving through the and mulling over the coded interview data. Their input has focussed our attention on aspects of the lived experience contained in the material that reflect wider social and cultural dynamics, which have serious implications for older people.

For instance, discussing the coded material about social networks, friends and family, it was pointed out by the co-researchers that many people had moved into the county from further afield to take advantage of lower house prices,the phenomenon of retirement migration, often affecting rural areas. But when this generation of new rural residents begin to need care, their social networks are not necessarily well-established enough to benefit from the kind of social capital we have seen that benefits others. This kind of perspective comes from the co-researchers wider personal experiences and it’s made us think more about how many people are managing the sometimes-onerous task of being a self-funder when they are without family or close friends and even more ‘on their own’ in the process of finding and funding care.

It's also been very helpful to have the co-researchers closely involved in dissemination activities and in shaping the outputs.

**Tony: What sort of advice would you give to your academic colleagues who are considering co-production in their research projects?**

I would say you have to have a real commitment to the ethos of co-production and be willing to start involving members of your particular interest group from the very start. You should be willing for them to help shape the research – this is what we mean by sharing power.

In terms of representation, we’ve got quite a range of different backgrounds amongst our co-research group, and there are four men and six women, all white, but they don’t necessarily ‘represent’ the older population in Lincolnshire. I think trying to get a representative sample of co-researchers is problematic. What I value in our group is that the CRs have enough common life experience to be able to empathise with our older research participants and yet are also consciously open-minded and reflexive enough to be conscious of our limitations and able to articulate the issues.

As the person who has most contact with the co-researchers and co-ordinates their activities, it’s been really important to build up a good personal relationship with the CRs as individuals and as a group. In practical administrative terms, keeping the communications going, keeping work flow on course and following through on their ideas for outputs – like the educational films - takes time, and that is really important to build into your research. We don’t meet in person and share sandwich lunches anymore, but those face-to face informal moments were crucial in building relationships and that kind of expense, along with travel expenses or perhaps now some help towardsremote-working technology, needs to be incorporated into research budgets. These ‘costs’ in time and funding have paid dividends in terms of the richness of the discussions we’ve had and the shape the research has taken and I hope on the impact of our research .

**Phoebe: Can you tell us a bit about the outputs of the project and the kindsof impactyou would like the research to have?**

Tony:

There are several outputs which can be identified from the Research Project over the3 year period. Some of the outputs have already been identified in terms of the Code Books and production of Resource Booklets for Older People or Carers entitled ‘As time goes by “ and “The Care We want “. We’ve also been involved in online presentations of research at the BSG and PEARL conferences this year.

Secondly, Co-researchers were involved in holding ‘café conversations’ with the public who attended a specially commission virtual reality artwork entitled “Care[less] presented at the Digital Frequency Festival last year and other public events where we displayed a 3D ‘Tree of Knowledge’ with ‘leaves’ containing statements drawn from the research interviews. This was a direct representation of the qualitative interview material revealing what people said “in their own words”.

Further products from the research are in the pipeline. Some Co-researchers have recently started work on writing and producing a series of short educational for social work students. This is work that has grown directly out of our move online and is a good example of how we have adapted our work over the last few months.

As far as impact goes, we would like to see

* Greater awareness and knowledge about finding organising and paying for care amongst older people and Carers;
* Greater awareness, knowledge and inclusion of of self-funders amongst in debates about the future of social care and .
* Greater awareness and knowledge of self-funders included in the education of students of Social work.
* Improved systems for providing advice and information on finding and paying social careby local authorities delivering Assessments and personalised Care Services as defined within the broad umbrella of the Care Act 2014.

Additionally , I hope that it possible that the findings from our research might influence the current programme evaluation on funding models in Social Care?[ ie. The Green Paper and beyond ? ]

Phoebe: Thanks Tony, I think we’ll let other people ask some questions now…

[hand back to chair person for Q & A]