

Learning From Older Citizens Research Groups: What Can We Learn From Older Citizens Research Groups?

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Learning From Older Citizens Research Groups: What Can We Learn From Older Citizens Research Groups?

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With the WhyNot! Older Citizens Research Group

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Abstract

This article adds to an ongoing conversation in gerontology about the importance of training and involving older people in research. Currently, the literature rarely distinguishes between the one-

off involvement of older citizens in research projects and the development of research groups led by older people that sustain over time as well as the nature of educational initiatives that support their development. This article presents a case-study based on evaluative data from the WhyNot! Older Citizens Research Group which has been running independently for nearly eight years. Members' evaluations of and reflections on the impact of the training programme, explore from their perspective: Why older people want to get involved in research training and research groups, what they value most in the training and the types of impact their involvement has had. Creating an educational environment where participants were able to contribute their knowledge in a new context as well learn new skills through group-work based experiential learning were key. Regular role-modelling provided by inputs from successful established citizen research groups was also important. Of the many benefits members gained from being part of a research group, emphasis was given to the *relational* aspects of the experience. Likewise the benefits members' accorded to taking part in training and research transcended individual benefits encompassing benefits to the collective and the wider community. Linking health, social care and educational policies is important in providing coherence and opportunity for older people's voices to shape research, policy and practice.

Keywords: older citizen research groups, older people and research

INTRODUCTION

This article adds to an ongoing conversation in gerontology about the importance of training and involving older people in research. There is a growing body of literature that explores the democratic rationale for involvement (Walker, 2007), recruitment to research studies (Mody et al., 2008) and innovative ways to involve older people in research training and

practice (Gutman et al., 2014). However, the literature rarely distinguishes between the one-off involvement of older citizens in research projects and the development of research groups led by older people that sustain over time and the nature of educational initiatives that support the development of such groups.

For the last seven years the authors have been involved in the training and arms-length support of four cohorts of an independent older citizens' research group 'WhyNot!' which formed after the first training programme was completed in 2007 (Munn-Giddings, McVicar, Boyce, & O'Brien, 2009). The academic team together with WhyNot! have been developing participatory methodologies to try and ensure that the unique experiential knowledge service users and carers have as individuals and as a collective can best inform health and social care practice and service development. We draw on the data from training evaluations, focus groups with members of WhyNot! and testimonials written by the group to provide a specific case-study addressing issues of:

- Why do older people want to get involved in research training and research groups?
- What do they value most in the training?
- What impact do they feel their involvement has on an individual and community basis?

We set the case study in context by tracing the development of citizen involvement in research as part of the wider agenda of user, carer and citizen involvement; considering whether particular issues arise for older people. Parallels are drawn with the aims of critical educational gerontology We conclude with a discussion of the wider social and educational factors necessary to support the development of research groups led by older people.

THE RISE OF CITIZEN RESEARCH

The context for the development of WhyNot! and citizens research groups more generally is the plethora of policies in the UK that began in the 1970s, galvanised in the 1980's, encouraging and increasingly mandating the involvement of service users, patients and the general public in the development and delivery of health and social care commissioning and services. Barnes and Cotterell (2012) make an important distinction between official policies that have promoted a largely 'consumerist' model of involvement and the democratic model embodied through autonomous action by service users, carers and citizens wishing to have their voice heard - most notably documented in the disability and mental health user movements (Beresford, 2002). The former approach has been largely (but not exclusively) influenced by economics and in particular in the UK by the introduction of a purchaser/provider split in National Health Service in 1990 (Department of Health, 1990) requiring purchasers to consult with potential service users and ensure their services reflected citizen need. In contrast the democratic model, led by the service user movement, is characterised not only by a demand for a voice in service development but also for a genuine change in the power relations between service providers (Beresford, 2002).

If experiential knowledge (knowledge gained through living with a condition/situation or context) is genuinely to be placed at the heart of health and social care development then this also requires a shift in who is shaping and carrying out the research that informs service development. Democratic traditions of research can be traced back to Paul Hunt's seminal critique of the 1960s research into disability by non-disabled researchers (Hunt, 1981), alongside the participatory research movement which in contrast to traditional forms of research is led by

and builds on the knowledge held by those facing the situation (Winter & Munn-Giddings, 2001).

In terms of official UK policy, the involvement of users and citizen in research became visible in 1996 in the Standing Advisory Group on Consumer Involvement in the UK NHS Research & Development programme (now INVOLVE) leading to national guidance on good practice in involving the public in research (Hanley et al., 2000). Since then the involvement of citizens or service users and carers in research has been mainstreamed in the UK with national funders requiring that applicants demonstrate how users/citizens have been involved in the development and sometimes the ongoing continuing involvement in the research process (for example, the UK's National Institute of Health Research -NIHR).

However 'involvement in research' is along a spectrum and can take place at any point or all points along the research process, from developing ideas and defining the research questions to undertaking research, analysing the data and writing and disseminating the results. Models of involvement abound and range from one-off involvement in a project, longer term involvement as a co-researchers (working for example alongside academic researchers), or groups led by citizen researchers. Support for involvement also varies considerably from no training, on the job training to in-depth training in all aspects of the research process.

THE INVOLVEMENT OF OLDER CITIZENS IN RESEARCH

Whilst the general move to the involvement of citizens in all aspects of service development includes older people, it is perhaps fair to say given the demographic and potential political influence (in terms of voting) rather less has been said about their involvement and there have been a number of reviews related to involving older people in research (e.g. Boyce,

O'Brien, Munn-Giddings, & McVicar, 2009; Fudge, Wolf, & McKevitt, 2007). Although prominence tends to be given to initiatives in mental health it is encouraging to note in a number of countries there are a variety of initiatives involving older people these take a variety of forms including collaborations with academics and/or policy makers (Bass & Caro, 1995), specific one-off opportunities to get involved with projects either at various points or throughout the research process. Very rarely are projects led by or predominately steered by older people themselves (Leamy, 2005).

it is clear that some form of training – either prior to the project taking place or ‘on the job’ learning research skills whilst carrying out the work - is necessary to enable older people to engage with research processes with some confidence (Peace, 1999; Peace and Hughes, 2010). Training varies from accredited courses (Clough, Green, Hawkes, Raymond, & Bright, 2006) to bespoke training (Gutman, 2013; Heslop, 2002) sometimes on specific aspects of research or complementary activities (e.g. see Dewar 2005 account of training in participatory appraisal). There are conflicting reports as to whether older people are attracted or ‘put off’ by the potential of qualifications in the area (Clough et al., 2006).

Benefits reported from both attending training courses and undertaking research tend to be reported by the researchers rather than older people themselves. For example, Bass and Caro (1995) suggest that the process of participation can be useful for older people in terms of learning more about social and policy issues as well as opportunities to help shape public policy. Macaulay et al. (1999) and Clough et al. (2006) all suggest self-empowerment possibilities in terms of collectives of older people enabling change in their own communities as well as skills for voluntary and community employment.

Concerns raised tend to reflect wider debates about citizen involvement rather than educational issues, such as cautioning against the cost and time involved in participatory research – particularly where funders have rigid deadlines and concerns as to whether initiatives are meaningful or otherwise (Scourfield & Burch, 2010). The socio-political aspects of who gets involved in research (in terms of age, ethnicity and class) and why are also raised but rarely elaborated. Other more ‘phase of life’ issues highlighted the potential difficulties in balancing the demands of a research project (particularly funded ones) with other aspects of ‘older’ people’s lives such as caring/grand-parenting and holidays representing a challenge (Blake, 1998). Further age specific concerns reflected ageist stereotypes which assume that growing older inevitably results in reduced physical and mental capabilities to get involved in research (Reed, Weiner, & Cook, 2004).

More recent writings in this area have tended to emphasise the importance of relational aspects of the work, acknowledging the importance of ethical practice by academic researchers with older citizen co-researchers (see Ward & Gahagan, 2012) as key to understanding involvement as potentially empowering (or otherwise). Peace has noted both in 1999 and more recently in 2010 the importance of offering a wide range of ways for older people to become involved in projects and finding ethical ways to promote involvement.

An interesting challenge that emerges is the difference in perceptions of older people and academic researchers on what constitutes ‘good research’ with citizen researchers prioritising impact on service deliver. Thornton (2000) noted that where projects were instigated by older people themselves they were more likely to be in areas that they believed presented opportunities to influence policy makers. Further that this also raises issues related to the post-training phase

with older citizens likely to get disenchanted and frustrated with the endeavour unless research opportunities followed training.

However, as noted above, reports and reviews on groups run by older people themselves remain limited. WhyNot! have also undertaken their own scoping review of other older people led research groups in the country (Stannard, 2011) and identified only six similar groups and only one other autonomous, constituted group like themselves. Core findings from their scoping review suggest that the instigation of the group either came through an initial training programme hosted by a University or through existing senior forums. Some members of research groups therefore already had a history of working with one another on older people's issues whereas others were meeting for the first time. The end result of courses/training was quite varied with half the groups continuing to take an active part in researching either for their community or collaborating with others. Some members of other groups continued on an individual basis, to conduct interviews for academic researchers. Groups brought together by academics for a specific purpose did not sustain after the end of that project. Across all six groups the majority of their projects were focussed on the needs and concerns of older people and projects ranged from local to national in scope.

PARALLELS WITH CRITICAL EDUCATIONAL GERONTOLOGY

It is interesting, that despite the literature highlighting the importance of training and support to both ethically and effectively involve older citizens in research, rarely are the health, social care and educational agenda's knitted together. Yet, looking at a variety of educational developments in their more critical forms can be seen to closely align with increasing the voice,

agency and involvement of older people. In particular, educational gerontology argues for a moral goal of learning in later life to develop alternative visions for democratic social change whereby older people are empowered to overcome various forms of discrimination (Hafford-Letchfield, 2014).

The roots of both lifelong learning and active ageing promoted both by EU and country specific policies (Department of Health, 2001; European Union, 2012) can also be traced back to concerns with social justice even if their manifestations are often (similarly to the involvement agenda) co-opted by the neo-liberal economic agenda. Learning opportunities, with health and social care participation opportunities offer what Hafford-Letchfield (2014, p. 433) describes as ‘a collective and negotiated enterprise with which empowerment could be promoted giving older people more control over their lives’.

In both the literature on involvement of older citizens in research and participatory forms of educational gerontology, a gap remains as to the experiences of older citizens who wish to develop skills that enable them not only to take part in research but potentially lead their own research *group*. In the next section of the article we present a case-study based on the WhyNot! Older Citizens Research Group which has sustained for nearly eight years. The case study focusses on members’ evaluations of and reflections on the impact of the training programme exploring from their perspective:

- Why do older people want to get involved in research training and research groups?
- What do they value most in the training?
- What impact does their involvement have on an individual and community basis?

Data are drawn from the ‘end of training’ evaluations of the four cohorts ($n = 44$) and focus groups conducted with members of WhyNot! during 2012 ($N = 17$), facilitated by the South Essex Service User Research Group. Data was thematically analysed by members of the academic team with members of the South Essex Service User research Group. Ethical approval was gained from Anglia Ruskin University for the focus groups.

CASE STUDY: WHYNOT! OLDER PEOPLES RESEARCH GROUP

WhyNot! Older People’s Research Group was established by a group of nine older citizens in 2007 following a 15 day training course, developed and delivered by the authors – who are academics at Anglia Ruskin University. The course was initially funded by Skills for Care, East and thereafter supported by Essex County Council. The course was free for up to 15 people including travelling expenses. Recruitment to the course has been through a variety of mediums including adverts in local papers, older people’s forums, chiropody vans and GP surgeries. The age threshold changed over the duration of the four cohorts, starting at retired and over 60 (to fit with County Council Older People Service criteria) but was adjusted for later cohorts by the group themselves to be more representative of (then) current trends for early retirement. The only other criteria that course applicants required were to be retired, commit to the full length of the course and to be prepared to work in small groups and have their views challenged. The last point being of particular importance in ensuring that participants became reflective and aware of the difference between their own, often very passionate views on a topic and the potential for others in their research to think and feel quite differently about the same matter.

TRAINING

The original course was developed following the in-depth literature review of existing initiatives (Boyce et al., 2009) and consultations with the older peoples planning forum and an existing citizen research group (CRG) the South Essex Service User Research Group (SESURG). Thereafter, the course was co-developed and delivered with members from the WhyNot! group. In total four cohorts of citizens have been trained from 2007–2014. The last cohort was funded through a grant from the UK Big lottery fund secured by the group itself.

The pedagogy of the course was informed by transformative learning theories (Kolb, 1984). These theories prioritise the importance of experiential knowledge and learning, which fitted well with the backgrounds of the academic team all of whom have many years of experience of supporting participatory approaches to research and capacity building across a range of areas with adults and young people in community, practice and educational settings. The format of the course was based on group-work principles with minimal input from tutors and a philosophy of ‘learning by doing’ within the classroom setting. The overall aims of the training were for participants to attain:

- a basic awareness and grasp of processes that inform key debates in older people’s research;
- new skills that they may use for personal or community project and;
- a starting point for a group or groups of people to perhaps go on to develop further skills.

Crucially, it was approached as building on the knowledge and skills that older citizens already brought to the educational setting.

The original programme had two phases: revised and co-delivered with WhyNot! for later cohorts. For the first three cohorts the course ran for 15 days and for the last cohort the course was a five day abridged version (due to funding restrictions) supplemented by ‘on the job’ training with group members on live projects. The course was supported by a resource pack which held training notes, related articles and a glossary of terms – the latter of which we built together as the course developed. As the course progressed it was common for participants to find related news cuttings which were added to group discussions and the resource pack **Table 1**.

To date 46 people have completed the training, of which nine were founding members of WhyNot!. Membership currently stands at 20. The majority of the applicants have been women (80%), predominately white British (90%) with ages ranging from early 50s to mid-80s with a median age of 65. Participants on the course came from a wide range of professional backgrounds including commerce, health and social care, accountancy and teaching. A minority of participants joined and completed the training having left school at 15 with no qualifications and a few participants have degrees, the majority have professional rather than educational backgrounds. Only four participants have previously done research. It is notable however that despite wide ranging adverts the majority of people coming forward for the course have previously been involved in some sort of group or community activity such as pensioners action groups, older people’s forums and self-help groups.

WHY GET INVOLVED IN RESEARCH TRAINING?

A range of reasons were given by those who applied to do the training many reflecting the desire to have an active retirement with accompanying educational, social and political aspirations. There was an understandable wish to use or build on previous skills or learn new

ones, although importantly the social and relational aspects seemed of equal importance. Prominent in the answers was the desire to improve things for people in older age including themselves.

People applying for the course were at various stages of their retirement journey – reflecting the age profile above. Those due to retire tended to frame their answers in relation to trying to ensure they had something stimulating and useful to look forward to in a new phase of their lives:

*I considered it would be very useful, particularly asking opinions from older groups
(Female, cohort 4)*

For some this was about refreshing previous skills as a few people who joined the group had been involved in education before and undertaken research as part of their career:

*Because I used these skills in my paid employment and wanted to meet with a group of
like-minded people (Female, cohort 4)*

For others there was an opportunity to bring their existing skills to a new venture:

*...I think we all bring different gifts and experience...its experience that's the word that
came out at the beginning and that's of value... (Female, cohort 1)*

For the majority though it was about learning new skills and the opportunity to take a new direction in retirement:

*It seemed a good opportunity to develop new skills, meet new people and spend time
constructively... (Male, cohort 2)*

Finally, the majority mentioned giving something back to peers and for older people in the future and contributing to the development of services they themselves might need:

...I'm getting older and I thought, well, it's about time you did something for older people... (Female, cohort 1)

...it was partly self-preservation, because I'm curious I need to know what is there in the future for me and with my experience of local government, working with elderly people, I thought I might be able to influence, help, learn, all kinds of things...(female, cohort 2)

WHAT DID PARTICIPANTS VALUE MOST IN THE TRAINING?

From the evaluations from each cohort it is clear that there have been some key aspects in making the course a success. All of these emphasise the importance of relational and aspirational aspects of the course.

Role-Modelling

Building in a role-modelling session from an established peer-led research group at both the start of the course and at the end seems to have encouraged participants to feel they 'can do it'. In cohort one this role modelling came from the mental health research group South Essex-Service User Research Group (SE-SURG) and in later cohorts both SE-SURG and WhyNot!.

...Inputs by established research groups...they can do it...we can do it ...why not!
(Female cohort 3)

Group-Work

The course was also highly interactive, based on group-work with minimal didactic input by tutors and a ‘learning by doing’ approach. For example, in small groups developing short interview schedules and focus groups – trying these out on each other and debriefing on the issues from both facilitators and participants. This enabled participants to learn from each other as well as the tutors:

...there were people in there with a great amount of related experience...when they came together it was value plus all the time...there was a resource there and they knew it (the tutors) and that made it for me, to be honest...(Male, cohort 2)

Participants brought a range of skills to the groups such as project management, chairing, book-keeping, typing, report writing etc. which have been invaluable in supporting the groups development. Working from the concerns and passions of participants also gave the course a focus and enabled us to explore the types of work a CRG could feasibly get involved in. As WhyNot! developed and began to input into the course some examples from actual projects which they had conducted really helped in giving participants a flavour of the types of work they could get involved with as well as the opportunities and challenges to be faced.

Meeting People and Building Friendships

As well as being attracted to learning new skills, the wider aspects of joining a group that was meeting consistently over time was appealing in terms of the potential to make new networks and potentially build friendships:

...the fact that everybody seemed to come from a different walk of life and brought something specific from their way of life, their career, whatever, their interests, whatever, that was good as it made it interesting, not only whilst we were doing the work that was

set on the course, but also at lunchtimes you chit chatted and that made it really social...
(Female, cohort 2)

It was striking that most participants talked about the opportunity to meet others with similar aspirations and in many cases this has led to friendships that transcend the meetings the group operates.

...I really enjoyed the company and looked forward to it really, coming each week and learning at the same time... (Female cohort 2)

For others the potential to make peer networks and have an influence was of particular importance given the demands in their personal lives:

The training gave me the opportunity to learn about research, which I would never have done without the course, gave me a life outside of caring, to feel that once retired you could be of value to society. I think it has given the group the opportunity to meet people from all walks of life, learn how others cope in difficult situations, make new friendships, feel that they are making a genuine contribution to their future by being involved in matters relating to older people, opens doors to other organisations (Female cohort 2)

Interestingly the majority of participants felt it was important that the course was held at a neutral setting (Council training suite and latterly at a community hall in a church) rather than the university which they felt may have been off-putting. This also applied to keeping assessment informal rather than qualification based as one member puts it:

I'm luckily at a stage when I'm life not career enhancing ... (Female, cohort 1)

IMPACT OF THE TRAINING: INDIVIDUAL AND COMMUNITY

Participants discussed a wide range of skills they had acquired during the course – including the technical research skills such as designing a questionnaire or focus group schedule but perhaps as importantly the social and influencing skills. Participants also discussed the impact on them as individuals in terms of confidence and new abilities to get involved in wider initiatives and the types of impacts these might have on the wider community.

Impact at a Personal Level

Even the personal benefits attributed to doing the course were framed in terms of both direct benefits to the individual as well as the potential wider impacts this might engender:

The training gave me a different view of the possibilities of research. The idea of service user research actually empowers the service user and has encouraged me to gain more understanding of social work and greater emphasis with the aspirations of older citizens. It has encouraged me to become more involved in other groups such as WEA and U3A as ways of giving older people enhanced lives (male, cohort 1)

And

I'd just like to blow my own trumpet perhaps for a minute; I gained a lot of confidence from that course, more than I expected, so much so that in the older people's planning forum, they were asking for a deputy chair and I've actually nominated myself. Whether I get it is another matter (they did) but It's given me another voice, another avenue,

another pathway of supporting older people and without this course I wouldn't have dreamed of putting myself up for that...(female, cohort 2)

Those who went on to join the OCRG were clear that they wanted to use the newfound skills and confidence:

...I wouldn't have wanted to do this course and had absolutely nothing at the end of it, I would have felt very let down...I felt I want to do something now with the knowledge I have gained...(Male, cohort 2)

Impact at a Systemic and Community Basis

The desire to influence local policy and practice was high on the motivating factors for both doing the training and joining the group. Answers reflected a desire to influence decision making from its inception (i.e. what is researched) to be part of using the results to influence systemic change.

...I thought that a lot of the time we don't ask the right questions, so how can we make anything work? I thought if I know more about research maybe I can put something into the questions that are asked in the first place. ...(Female cohort 2)

And

I wanted to increase my knowledge on how we can improve feeding that information into the system... (Male cohort 2)

Networking

The development of the group also put members in touch with wider user involvement initiatives and the additional skills and confidence that members gained have been used in other

forums. For example, several members of the group now sit on the user and carer group at the local university influencing social work curriculum design and delivery. They are also members of the local council's research and development governance committee.

I think it makes you realise when you do something like this that there is a lot more to be done surrounding older people, vulnerable people particularly...and a lot more we can all do to help... (Female, cohort 2)

An important development in the history of the group has been the way in which members start to use the research skills they have gained to impact on other aspects of their lives –embedding the social capital beyond the confines of the group:

...as a result of being in WhyNot! and doing the course I've met other people, I sit on interview panels...that spends millions on the training of staff...and get invited to these things...so there are 'spin offs' ...I'm not on the scrapheap yet!... (Female, Cohort 1)

An important aspect of the 'spin-offs' was the use of skills in other contexts outside the immediate work of the group. One of the founding members discusses how she used her skills to address a local issue. Living in a rural village with no shops and where over half the population were aged sixty plus she became concerned when, without warning, the local bus service was reduced to once an hour and re-routed through an estate. Many residents were forced to carry heavy shopping over half a mile. So she used her new research skills to design a transport survey in her local parish – the results of which were used in a funding submission to the local council to reinstate the bus service.

...Without the training I had received none of this would have been possible and our older residents would be struggling to make their way to and from the bus stop...the

services continue to be well used - a blessing to the local community, enabling older people to live more independently in their own homes. (Female cohort 1)

Postscript

Since 2007 WhyNot! have been involved in 16 projects as direct commissions from the County Council, District Councils, NHS and Age UK which we have supported on a 'needs-led' basis. They have also been contributing to an international project at the university (Gutman et al., 2013). Throughout the development of the group the tri-partnership between champions in the county council, the university and the group itself has provided an underpinning, sometimes invisible support structure to assist the group move from fledgling to mature. The county council not only provided the training venues for all cohorts but continued until recently to cover travel costs for the group and in its early years a members of the community engagement team attended meetings to look for opportunities for the group to get involved in relevant local projects and assist them as required in developing the group. However, as economic austerity has hit the council in recent years with a resulting loss of funding and of the individuals who championed the group WhyNot! has evolved to be self-funding and self-governed having a constitution and membership.

DISCUSSION

The case-study above provides us with some insight into why older people want to be involved in both educational activities understanding more about research that affects older people as well as why they want to continue their involvement, over time, in a research group.

The types of benefits from both the training and use of their research skills that group members discuss echo many of the earlier findings in the literature review such as increased

confidence, development of existing skills and learning new skills they can use to enhance both their own lives and the broader community of older people (Boyce et al., 2009). By getting involved in group activities and processes where they also contribute skills developed in informal or formal working situations they were able to bring these to maximum advantage to contribute both to the educational experience for participants on the course as well as the development of the citizen research group.

Creating an educational environment where participants were able to contribute their knowledge in a new context as well learn new skills through group-work based experiential learning seems key here. As was the regular role-modelling provided by inputs from successful established citizen research groups. The development and sustained commissioning of WhyNot! is testament to the potential for older citizens not only to get involved in research but run their own projects.

Of the many benefits stated above that are gained from being part of a research group, it is important to note the emphasis given to the *relational* aspects of the experience. These relational aspects are of particular importance when we consider what underpins the success (or otherwise) of the educational aspects of the training as well as the potential for a group to form and sustain post training. Members of Whynot! expressed the importance of meeting like-minded people and the friendships and networking opportunities that ensue. The literature reviewed, whilst making some generally useful points about older citizens involvement in research, equally rarely distinguishes between an array of models ranging from one-off involvement in projects with people who either know each other or are meeting for the first time, co-production models with older citizens working alongside academic researchers or groups led by older people themselves. Likewise to date the benefits that are accorded to older citizens taking part in

research have largely been focussed on individual benefits rather than the benefits to the collective and the wider community (whether geographical or interest community). The findings above illustrate how benefits impact beyond the individual level to the wider community of older people.

As was noted earlier a defining feature of user and citizen involvement in both the UK health and social care system and indeed many related involvement and educational strategies is that they are predominately individualistic in nature, with little difference being accorded to the type of knowledge that individuals vis-a-vis collectives of people, develop in relation to their direct experience of a health or social situation or phase of chronological age. This is not surprising given the ‘consumerist’ models of involvement that tend to predominate. However, the distinction between individual and collective knowledge and voice is important.

Getting involved as an older person in a citizen research group therefore raises questions not only of individual voice and agency but also of ‘collective agency’. In Older Citizen Research Groups, older people as a collective, are challenging stereotypes of this phase of their life and carving role(s) that put to rest more negative stereotypes of aging. Citizen research Groups are both trying to improve the lot for older people per se as well as for themselves at a near point in the future but they are doing this with and through a group process. Wray, 2004 suggests that if what it means for an older person to be independent and act autonomously is theorised as *social* rather than individual this changes how agency and successful ageing are understood prioritising interdependence and involvement with others.

CONCLUSION

Our understanding of the particular features of sustained older citizens' research groups in comparison with other models of involving individual older people in research is only just starting to develop. Yet in all country contexts the benefits for collectives of older people that this form of involvement can offer is of significance. It is important to promote educational initiatives that engender collective agency and voice, particularly in countries dominated by policy and practice climates that focusses on individualisation. Groups like WhyNot! have much to contribute to local and national agendas perhaps their greatest threat is how to sustain in our current global situation of austerity and cutbacks. Linking health, social care and educational policies is important in providing coherence and opportunity for older people's voices to shape research, policy and practice.

ETHICAL APPROVAL

Ethical approval was gained from Anglia Ruskin University for the focus groups – all other data is in the public domain (funder's reports, REF case study).

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DECLARATION OF CONTRIBUTION OF AUTHORS

Carol Munn-Giddings was the lead author – all other named co-authors contributed ideas to the paper and provided regular written feedback on drafts. Co-authors were also involved in the design and delivery of the educational programme and associated evaluation.

DECLARATION OF ORIGINALITY

This manuscript has not been published elsewhere nor submitted for review to another Journal.

CONFLICTS OF INTEREST

None

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Table 1. Outline of the training programme

■Phase 1: essentials of research including:
■Service user and citizen research (intro), peer-modelling by SE-SURG members + after the first cohort with members from WhyNot!
■Literature review, developing a research question, overview of quantitative, qualitative and participatory research, common methods used in the context of research questions developed by the group. Sampling, data collection, analysis, ethics and dissemination. Sessions from cohort 2 onwards included ‘live’ examples and reflections from WhyNot! OCRG.
■Phase 2: putting learning into practice.
■Based on small groups designing a research project of interest to them and presenting it to each other. Critiquing including ethical issues and processes. Developing an evaluation of the course that is completed by all on the last day
■Revisiting the opportunities and challenges of Citizen research (with SESURG and WhyNot!)
Planning an ‘ending’ together with a celebration of achievement (certificates of attendance), shared lunch and opportunity to meet the wider WhyNot !group.