Developing a model of participatory research involving researchers, practitioners, older people and their family carers : An international collaboration

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What is This?

Developing a model of participatory research involving researchers, practitioners, older people and their family carers

An international collaboration

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Abstract   The care of frail older people and their family carers present significant challenges for welfare systems throughout the world. In order to address their needs, policy initiatives are promoting partnership working between service users, family carers and providers, whereby the former are increasingly involved in the design and evaluation of services. However, participatory models of working raise fundamental issues about power relations and pose important questions about what constitutes 'evidence'. Several authors identify tensions between movements such as evidence-based practice and initiatives designed to increase the active participation of service users suggesting that there is a need for a new approach to research that reconciles potentially conflicting goals. This paper describes the evolution of a model of participatory research resulting from a collaboration between Sweden and the United Kingdom, which actively involved older people, family carers, service providers and voluntary organisations. The model is underpinned by constructivist principles that have been adapted by the authors so as to be more intellectually accessible to a non-academic audience. The conceptual basis for the model is described and a case study illustrates how it is applied in practice. It is argued that the approach could be

adopted widely as a means of more fully engaging older people, their families and a range of service providers in important debates about future health and social care provision.

Key words   older people, participatory research, evidence-based practice, constructivism

Introduction

Despite the existence of differing welfare systems, countries throughout the developed world are facing similar health challenges, with demographic changes and the rising incidence of chronic illnesses being amongst the most significant. In addressing these challenges, researchers and policy-makers are increasingly promoting the formation of partnerships between formal and family systems of care in order to meet the needs of frail older people who require support to remain in their own homes (Kröger, 2003; Audit Commission, 2004; Banks, 2004; Nies, 2004; Scottish Executive, 2005).

Simultaneously, user and carer involvement in service design, delivery and evaluation have become part of the language of social policy, underpinned by notions such as empowerment, participation and partnership (Bernard and Phillips, 2000). Therefore, both older people and family carers should, in principle, be more actively involved in research, not simply as subjects, but in helping to identify important questions, in shaping methodology and also in data collection, analysis and the dissemination of results.

With respect to nursing research, these developments have coincided with the movement away from research-based practice to evidence-based practice (EBP) (Rolfe, 1999), which, according to some authors, has become 'the mantra of the moment' (Jennings and Loan, 2001). However, authors argue that there are distinct tensions between EBP and initiatives promoting user and carer involvement (Kitson, 2002), with Humphries suggesting that, whilst concepts such as user participation are 'part and parcel' of a more inclusive social policy agenda, EBP is a 'practitioner engineered movement', incompatible with the rhetoric of participation.

Consequently rather than users and carers being 'active shapers of knowledge and subsequent action' (Clough, 2005), it is contended that EBP has resulted in a biasing of research towards a professional's view of the world, rather than a user's (Kitson 2002), and that users are still seen primarily as sources of data, data which are subsequently used to develop professionally designed services and outcomes (Humphries, 2003).

Such debates raise fundamental issues of power, expertise and evidence (Owen, 2005), and beg the question as to 'what counts as research, and whose research counts?' (Nolan, 2005). If current and emerging initiatives such as the 'expert patient programme' (Donaldson, 2003), and the identification of 'expert family carers' (Scottish Executive, 2005) are to stand any chance of being maximally successful, then mechanisms have to be devised that enable all forms of evidence to 'come equally to the table' (SCIE, 2003). This will mean bringing together the varying but potentially complementary forms of evidence generated by researchers, practitioners and users/carers.

This paper describes a 10-year ongoing collaboration between the University College, Borås, West Sweden, and the School of Nursing and Midwifery, University of Sheffield, that has resulted in the development of a model of participatory research

involving researchers, practitioners and older people. It will briefly consider the genesis of the model, outline some of the various projects that have been undertaken, and illustrate how the model works in practice.

Establishing collaboration

Research collaborations emerge in many ways but, to be successful, and to stand the test of time, they need to be underpinned by shared beliefs and interests, solid theoretical and conceptual foundations and address issues of enduring significance and importance.

Collaborative work between the University College, Borås, Sweden, and School of Nursing and Midwifery at the University of Sheffield, UK, began in 1996 when these institutions were co-applicants (along with colleagues from the University of Ulster, Northern Ireland, The North Western Health Board, the Republic of Ireland and The Escola Superior de Enfermagem Dr Ângelo da Fonseca Coimbra Portugal) on a successful bid to the European Union (EU) under its Fourth Framework Programme, the Telematics Integration for Disabled and Elderly section (TIDE). The project, ACTION (Assisting Carers using Telematic Interventions to meet Older People's Needs), explored the use of Information and Communication Technology as a means of supporting family carers of older people in the five participating countries. At the time of the award, it was the largest nursing-led project ever funded by the EU. Theoretically the study was informed by the 'carers as experts' model and the temporal model of family care developed by Nolan et al. (1996). Its main aim was to provide family carers with appropriate support at key transition points whilst also acknowledging and actively drawing upon carers' own expert knowledge. The results of the initial ACTION project have been fully reported elsewhere (Hanson et al., 1999a, b; Magnusson et al., 1999, 2002a; Hanson and Clarke, 2000; Magnusson and Hanson, 2003).

The original ACTION project fully involved practitioners, carers and older people in the design and evaluation of a multi-media support programme and laid the foundations for a participatory method of working. As the initial EU project was drawing to a close, additional funding was obtained from the Ministry of Social Affairs in Sweden to further develop and evaluate the ACTION model in two municipalities in Sweden (Magnusson et al., 2002b). This initiative elaborated upon Nolan et al.'s (1996) original carers as expert's model, and more fully incorporated the PREP model of carer support (Archbold et al., 1995) into the programme. This approach actively seeks to address carers':

PReparedness — for their role.
Enrichment — by improving the relationship between the carer and the cared-for person.
Predictability — by helping carers to consider what the future might bring.

During this project, links with Sheffield were further consolidated with one of the authors (MN) acting as lead scientific advisor to the Swedish ACTION project.

ACTION cemented the burgeoning interest in the needs of older people and their carers in Borås, and also built on long-standing work at the University of Sheffield (Nolan et al., 1994, 1996, 1998) by promoting a more participatory approach to research. As the Swedish ACTION project was evolving, there was a call by the Ministry of Social Affairs in Sweden for the development of regional Centres of Research

Excellence on the needs of older people, which formed part of a larger policy initiative concerning older people and their family carers. Following detailed discussions and planning, it was decided that the University College, Borås, in collaboration with local and regional partners, and the academic support of colleagues in the University of Gothenburg, Chalmers Technical University and the University of Sheffield, would submit a bid. This was successful and the ÄldreVäst Sjuhärad (ÄVS) Research Centre was established.

The philosophy of the ÄVS Centre

ÄldreVäst Sjuhärad is a research centre focusing on the support and care of older people and their carers. The Centre is supported by: the Department for Social Affairs for Sweden; by six municipalities in West Sweden (Bollebygd, Borås, Mark, Svenljunga, Tranemo and Ulricehamn); the county council of West Sweden; one private care provider (Riksbygggeb West); the Swedish telecommunications company (Telia PubliCom AB); and the University College of Borås. The six municipalities funding ÄldreVäst Sjuhärad form one area named Sjuhärad, located to the east of Gothenburg in West Sweden.

The mission of ÄVS is to enhance the quality-of-life of older people and their family carers by working in partnership with them and by supporting the partners of the Centre in the provision of high quality care. The overall aims of the Centre are:

- Promoting cooperation and partnerships in shaping the direction and quality of health and social care and medical treatment.
- Enhancing the sharing of perspectives and experiences between older people and their families, professionals, voluntary organisations, health and social care providers and researchers.
- Increasing the opportunities for professionals working with older people to initiate, participate in and evaluate new research-based interventions and service developments.
- Raising the awareness and competence of care professionals to ensure the future quality of health and social care and medial treatment through their involvement in programmes of research, development and education.

Early debates about the mission and philosophy of the Centre were informed by the call for a value-based approach to work with older people proposed by Bernard and Phillips (2000), who outlined four values that should be employed:

- Positive, intergenerational, life course perspective
- The need to combat all forms of discrimination
- An empowerment approach based on citizenship and giving voice, which create new ways of working with older people
- A model that combines critical commentary with action for change

From the outset, one of the major goals of ÄVS was to develop a model of working that would, as Barnes (1999) advocates, create a 'meaningful dialogue between the abstract knowledge of professionals and the particular situated knowledge of those who use services'. This is consistent with approaches that 'blend' the 'cosmopolitan' (generalised theoretical and experiential) knowledge of professionals with the 'local' (personalised) knowledge of users and carers (Harvath et al., 1994). Such a stance acknowledges that no single person is *the* expert, but rather that all individuals have knowledge that is potentially useful. However, rather than adopt traditional partici-

patory research approaches, where the focus is primarily on generating 'knowledge for action' rather than 'knowledge for understanding' (Tetley and Hanson, 2000), ÄVS wanted to develop a model that would potentially achieve both goals.

Our thinking was informed by the constructivist approach to evaluation first articulated in the field of education (Lincoln and Guba, 1985; Guba and Lincoln 1989), and later applied to other practice disciplines (Rodwell, 1998). Rodwell (1998) contends that constructivism is an approach that is not only relevant for research, evaluation and change, but also provides a basis for practice, seeking as it does to bring together the perspectives of all those involved in a particular study or initiative in order to promote a shared understanding. Although Rodwell's focus was social work, the principles she articulates apply equally to a range of disciplines within the health and welfare fields.

Moreover, according to Rodwell (1998), constructivism not only promotes action and change, but is also concerned with developing theoretical insights. This link between constructivism and the development of theory has also been promoted by others (Charmaz, 2000).

In operationalising the ÄVS model, the following principles were developed:

- Listening first and foremost to the voices of older people and their families. This involves gaining their views and suggestions for developing and improving services.
- Hearing the voices of service providers and managers, including voluntary organisations for older people and their families
- Having a concern for the quality of the entire research and development process, and not simply the quality of the end product or service
- Initiating change and action whilst, at the same time, contributing to knowledge building
- Bringing together research, action, participation and theory-building

Having decided to adopt such an approach we also wanted to develop a means of evaluating our endeavours and thereby answering the question posed by Bradbury and Reason (2001) of how would we know if 'we are doing good work?'.

Evaluating the work of ÄVS

In terms of evaluating the work of the ÄVS Centre, we were drawn to the authenticity criteria originally articulated by Lincoln and Guba (Lincoln and Guba, 1985, 2000; Guba and Lincoln, 1989). Although proposed some time ago these criteria (see Table 1) have never been fully elaborated upon, nor have their relevance and applicability been widely tested.

Table 1 Authenticity criteria for constructivist research

Fairness	Are the voices of all the major interest groups heard? (That is, are all their opinions listened to and valued?)
Ontological authenticity	Does the study provide participants with new insights into their own situation?
Educative authenticity	Does the study help participants to better understand the position of other interest groups?
Catalytic authenticity	Does the study stimulate or identify areas for change?
Tactical authenticity	Does the study facilitate, enable or empower change?

(After Rodwell, 1998; Lincoln and Guba, 2000)

However, whilst we were persuaded by the sentiments reflected in these criteria we were concerned about how intellectually accessible they would be to ÄVS stakeholders, especially practitioners, older people and their family carers. What meaning would words such as 'ontological authenticity' have for such individuals? A decision was therefore made to re-label the criteria, whilst at the same time keeping, as far as possible, their original intent. We therefore renamed them as follows:

Original criteria	ÄVS criteria
Fairness	Equal access
Ontological authenticity	Enhanced awareness of own views/opinions
Educative authenticity	Enhanced awareness of views/opinions of other stakeholders
Catalytic authenticity	Encouraging action
Tactical authenticity	Enabling action

(Nolan et al 2003)

These ÄVS criteria are used at all stages of the research and development process, beginning with the planning stage, incorporating the undertaking of research itself, and are also applied to the dissemination of the products of research. This relationship is depicted in the matrix below:

	Planning	Process	Product
Equal access			
Enhanced awareness			
Self			
Other			
Encourage action			
Enable action			

(Nolan et al., 2003)

These criteria are used as a basis for reflection at several stages of the research process. Clearly, it may not be feasible or desirable to tick all the boxes for every project, as this would depend on the nature of the particular project, and would be discussed and agreed on at the outset by the key stakeholder groups involved.

In order to meet the above criteria, user involvement is actively sought at the planning phase of all projects and initiatives so that the main stakeholder groups play an active role in the choice of studies and activities that are undertaken in ÄVS. Key user groups also have an active say regarding the aims and objectives of the study, as well as how it can best be conducted. User involvement is maintained during the implementation phase of a project (the process stage) by regularly obtaining the views and experiences of the users involved, using both quantitative and qualitative research methods, such as focus group interviews, questionnaires and field notes. Where appropriate, users are actively involved in collecting and analysing data. User engagement is also sought at the final stage of a project when the results are written up and disseminated (the product stage), so that the project findings are accessible to as many people as possible. This is achieved by publishing a regular newsletter which gives a clear and concise summary of project findings and is widely distributed across West Sweden. A series of reports are also produced by ÄVS and these are advertised within the newsletter and are available free of charge on request. Finally, the professional and academic communities are engaged by ensuring that research findings and innovative ways of working in ÄVS projects are published nationally and internation-

ally in a range of professional and academic peer-reviewed journals, and via presentations and attendance at regional, national and international conferences. In this way, it is hoped that an active contribution is made to knowledge building by encouraging critical dialogue between users, practitioners, researchers and policy-makers in the field.

Since its inception, the Centre has been engaged in a wide range of activities. The ACTION project continues to gather momentum and has been highly successful (see Magnusson et al., 2005a). Indeed, it represents one of the few instances where an
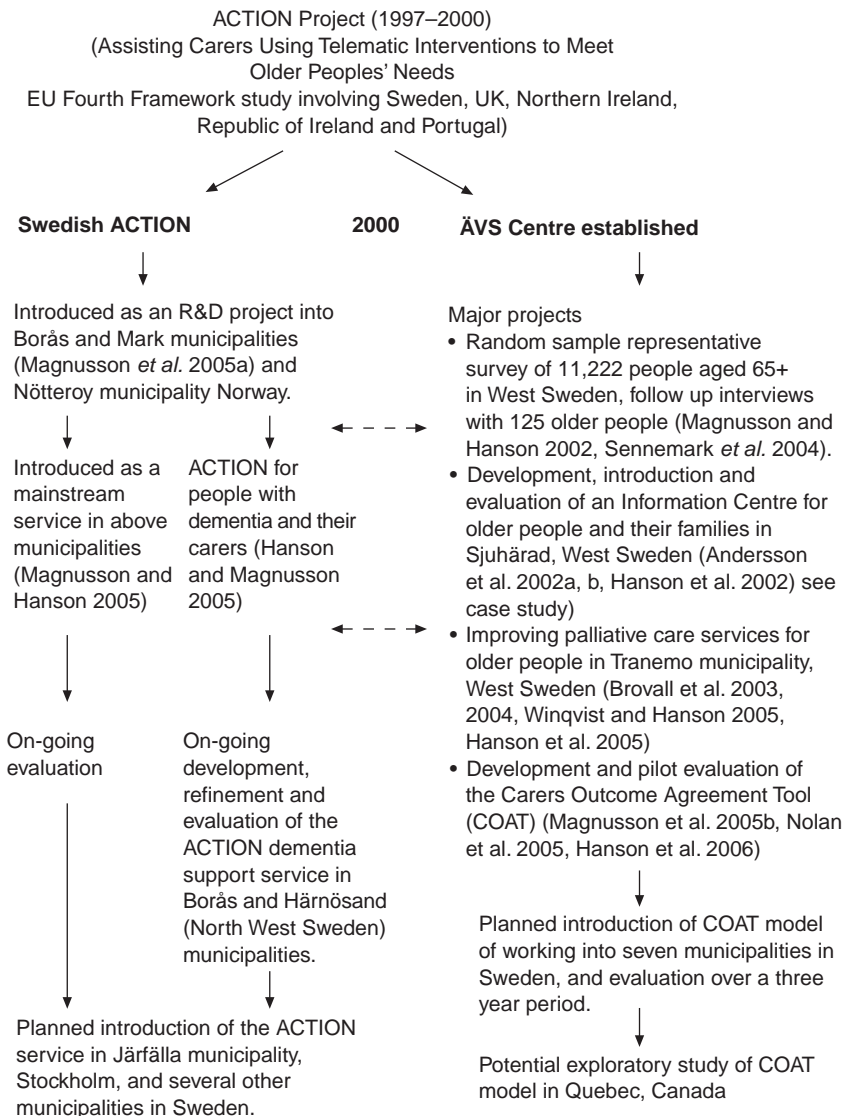
ACTION Project (1997–2000)
(Assisting Carers Using Telematic Interventions to Meet Older Peoples' Needs
EU Fourth Framework study involving Sweden, UK, Northern Ireland, Republic of Ireland and Portugal)

Swedish ACTION   2000   **ÄVS Centre established**

Introduced as an R&D project into Borås and Mark municipalities (Magnusson *et al.* 2005a) and Nötteroy municipality Norway.

Introduced as a mainstream service in above municipalities (Magnusson and Hanson 2005)

ACTION for people with dementia and their carers (Hanson and Magnusson 2005)

On-going evaluation

On-going development, refinement and evaluation of the ACTION dementia support service in Borås and Härnösand (North West Sweden) municipalities.

Planned introduction of the ACTION service in Järfälla municipality, Stockholm, and several other municipalities in Sweden.

Major projects
• Random sample representative survey of 11,222 people aged 65+ in West Sweden, follow up interviews with 125 older people (Magnusson and Hanson 2002, Sennemark *et al.* 2004).
• Development, introduction and evaluation of an Information Centre for older people and their families in Sjuhärad, West Sweden (Andersson et al. 2002a, b, Hanson et al. 2002) see case study)
• Improving palliative care services for older people in Tranemo municipality, West Sweden (Brovall et al. 2003, 2004, Winqvist and Hanson 2005, Hanson et al. 2005)
• Development and pilot evaluation of the Carers Outcome Agreement Tool (COAT) (Magnusson et al. 2005b, Nolan et al. 2005, Hanson et al. 2006)

Planned introduction of COAT model of working into seven municipalities in Sweden, and evaluation over a three year period.

Potential exploratory study of COAT model in Quebec, Canada

Figure 1 The genesis and evolution of ACTION and the ÄldreVäst research model

R&D project has been introduced as a routine mainstream service in both West Sweden (Borås and Mark municipalities) and Norway (Nötteroy municipality). ACTION will also shortly commence as a demonstration project in several other municipalities across Sweden. This success has only been possible by engaging key decision-makers throughout, thereby demonstrating the benefits of the ÄVS model.

More recent work with ACTION has seen the active involvement of people with dementia and their carers in the initial design and evaluation of a multi-media programme for people with dementia (Hanson and Magnusson, 2005). This programme has now been introduced into the homes of 10 people with dementia and their carers, and funding has been secured from the Knowledge Foundation in Sweden to continue this innovative work for a further three years. Alongside ACTION, several other studies have been undertaken since the Centre's inception, and these are briefly summarised in Figure 1.

In order to better illustrate the work of the ÄVS Centre, a brief description of the development and evaluation of the Information Centre initiative is presented below.

The ÄVS Model: a case example — The ÄVS Information Centre project

This project commenced in the spring of 2001 with the support of national funding from the Ministry of Social Affairs, Sweden, and additional monies from the ÄVS Research Centre. User representatives from local voluntary organisations for care for older people, as well as health and social care professionals, actively participated in the formation of the Information Centre. The purpose of the project was:

- To increase the quality of everyday life, as well as quality of care for older people and their families by enabling improved access to information and advice in several areas, including health and social care issues such as the range of services and activities available locally
- To make an active contribution to reducing the social isolation prevalent amongst house-bound older people and their family carers by creating opportunities for older people and their families to develop social support networks
- To make an active contribution to decreasing anxiety and depression amongst older people and/or their families by offering psychosocial support as appropriate

The service was provided via a multi-media approach, consisting of the choice of a free telephone line open every day of the week between the hours of two and, initially, ten o'clock, as well as the use of videophone and/or website with the possibility of sending email questions.

The ÄVS model for development and evaluation was used during all stages of the project, and there was active participation by the key stakeholder groups regarding the ongoing development and evaluation of the project. These included the callers to the Information Centre as well as the call operators, comprising both voluntary and professional representatives. The evaluation explored to what extent there were opportunities for all stakeholders to *influence* the research process and to have their voices heard. Also, we wanted to know if those involved had increased their awareness and/or understanding of their own situation and the situation of other stakeholders. Finally, we wished to find out whether the Centre had enabled key groups

to identify areas for change, and to what extent the project had empowered older people and their families to take action to change their situation for the better.

Key elements within the project included the following:

- The recruitment of interested volunteers from local voluntary organisations for care for older people, and fostering active working relationships with these organisations throughout the project
- The recruitment of interested and experienced personnel from health and social care for older people
- Educating the personnel involved in the goals of the Information Centre
- The development of a working policy for the Information Centre making explicit our ways of working in cooperation with the project's reference and expert groups
- A user-friendly website with information of interest and relevance to older people and their families was developed in partnership with a range of older people who formed a local user group to advise about the content and 'look and feel' of the website
- An extensive marketing campaign, including a television commercial, regular airing on local radio and a postcard delivered at two points in time to all households in Sjuhärad

Evaluation of the project included analysis of the telephone logging data as well as interviews with a number of consenting callers to the centre. Interviews were also carried out with the call operators and focus groups undertaken with the reference and expert group members.

An analysis of the telephone logging data during the period from September 2001 to May 2002 revealed that women phoned more often than men, half of the callers were family members and most of the calls lasted longer than five minutes. Calls often began as simple questions which subsequently turned out to be about more complex issues which required active listening and a considered response on the part of the call operator.

The evaluation process is illustrated in Figure 2.

Issues of concern to callers included the situation for older people in society in general, problems of social isolation and ensuing loneliness, the situation of family carers and the lack of accessible and user-friendly information and support. Most frequently asked questions centred upon welfare rights, requests for social activities and support, complaints and concerns about sick and frail older relatives.

At a follow-up interview, involving a range of consenting callers to the IC, many participants provided unsolicited positive feedback about the ways in which they had been treated by the call operators. The majority considered that they had had the time they felt they needed and had felt supported in their situation. Participants also emphasised the importance of being able to call anonymously and to speak with people who had knowledge of the issues affecting older people and their families, as well as those who shared similar personal experiences to their own. Furthermore, they commented on the importance of there being a service such as the Information Centre. A number of callers also wanted the Information Centre to play a more active support role by offering direct help.

The experiences of the staff reflect the positive responses of the callers to the IC.
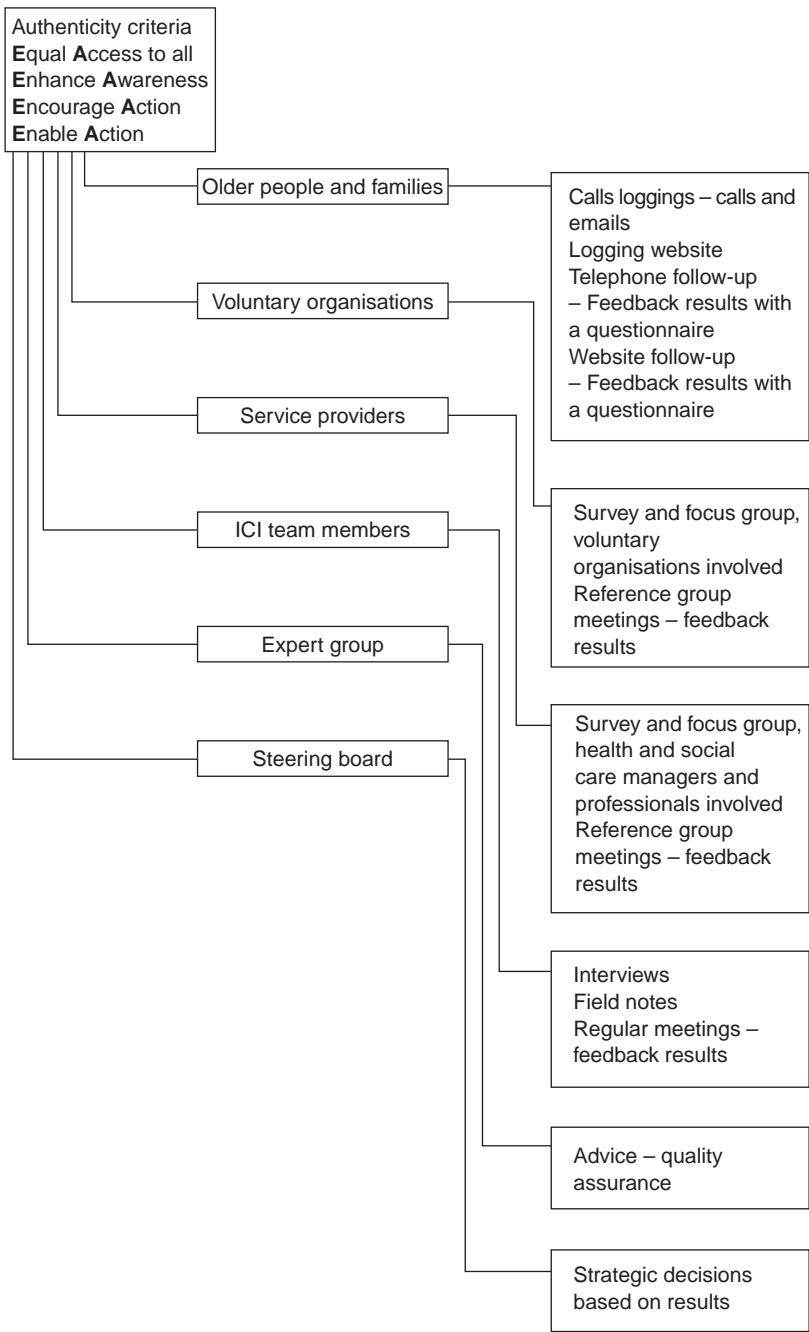
Figure 2 Evaluation of the Information Centre: model and methods

They explained how they were personally affected by the accounts of some of the callers, particularly the intense feelings of isolation expressed by some of the older people. They also considered that they had further developed their skills and knowledge. The professional call operators highlighted the experiences they had gained by working in partnership with the voluntary workers. They felt that this would greatly benefit them in their everyday work with older people and their families.

Table 2 illustrates how the ÄVS criteria can be used to provide further insights as to whether or not the Information Centre was 'doing good work'.

Discussion

The last decade has seen a significant change in orientation in the fields of health and social care, with much greater emphasis being given to the direct involvement of users and carers, in service design, delivery, evaluation and research. Consequently, there have been a number of policy and practice initiatives aimed at establishing partnerships between academics, practitioners and those in receipt of services. This has resulted in far greater recognition that differing types of knowledge and expertise can be brought to bear in determining the issues that are seen as important and the methods that can be used to answer pressing questions. Such developments have raised fundamental challenges for researchers and practitioners, and called into question traditional ways of working and existing power relationships (Kitson, 2002; Humphries, 2003; Clough, 2005; Owen, 2005). Therefore, while the principle of user and carer involvement is now widely accepted, how such ideals can be realised, and the criteria that can be used to judge their 'success', are less certain (Bradbury and Reason, 2001).

As noted in the introduction, several commentators argue that there is a tension between movements such as EBP and current initiatives to promote greater user and carer involvement in service design, delivery and evaluation. Recently there have been calls for a more inclusive definition of evidence-based practice so that decisions about care are primarily made by those receiving care, informed by the tacit and explicit knowledge of those providing it, within the context of available resources (Dawes et al., 2005). However, if this is to be achieved then, in terms of research at least, there is a need to 'transform the rules by which the game is played' (Barnes, 2002). This is essential if a more diverse view of evidence is to emerge (Rolfe, 1999; Ryecroft-Malone et al., 2004). The importance of this cannot be over-estimated for, as Gaventa and Cornwall (2001) note

> knowledge, as much as any resource, determines definitions of what is considered important, as possible, for, and by whom. Through access to knowledge and participation in its production, use and dissemination, actors can affect the boundaries, and indeed the conceptualisation of the possible.

A crucial question, therefore, is, do we see older people and their carers as 'actors', and if so are they able not only to access knowledge, but to participate fully in its production, use and dissemination? (Nolan, 2005). The logistical challenges of engaging older people and their carers must not be underestimated, particularly those who are cognitively or physically frail, socially isolated and hard to reach. Space does not permit a discussion here of how such barriers might be overcome, but suggestions are available elsewhere (Davies and Nolan, 2003).

Fundamentally, however, there is a need for a change of philosophy and approach if we are to overcome the limitations of

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Table 2 ÄVS model matrix with examples from the Information Centre project

	Equal access	Enhanced awareness of — self or — others	Encourage action	Enable action
Users	The logging and follow-up interview data revealed that the majority of callers felt they were listened to, and could easily access the system. For example, a daughter who rang to find out about a befriending service for her housebound mother explained: *'We talked for a long time and that poor woman on the other end* [of the phone] *. . . that day I felt so down and helpless. So I also got to talk about myself too — even if you've got relatives, sometimes it's so good to talk.'*	The logging and follow-up interview data highlighted that the majority of callers felt that they had received the information, advice and/or support they needed to help them better understand their own situation. For example, a retired man rang to talk about his concerns about the well-being of his wife who lived in a nursing home and whom he visited daily. He was able to talk at length about the situation and he received advice about suitable options open to him for resolving the situation, including tips about how to talk openly with the staff about his concerns.	Personal situation: Over three-quarters of users who took part in the follow-up interviews felt that their call had directly helped them with their situation. For example, a daughter who rang about her mother with dementia who lived alone and had started wandering explained how she felt the call had made her feel stronger and better able to challenge the support that she was getting: *'I felt that I had a bit more guts to stand up to the municipality.'* Generally: Over half of the participants that took part in the follow-up interviews gave concrete suggestions about how the IC	The follow-up interview data and the call operator interview data give vivid examples of how callers were empowered to take action with regards to their own situation. For example an older man who rang because he was being threatened by illegal immigrants explained: *'The postcard* [explaining about the IC] *came at just the right time, it was good that someone answered straightaway when I rang and I didn't need to wait to talk to someone. When you call* [to public services] *you often have to wait and then you have to talk to different people before you get in touch with the right person. I was so frightened and after the call I felt able to get in touch with the police and talk about my situation. I've got nothing but praise for the IC'.* A daughter who rang about a family conflict concerning how to best

Table 2 continued

Equal access	Enhanced awareness of — self or — others	Encourage action	Enable action
		could be further improved, this mainly involved the IC playing a more proactive role in the local *community*. For example: *'You could go out and visit them* [older people and their carers] *in their own home and talk with them and also go and talk with them on the different wards and in the nursing home — talk with the older people and say that they can ring you up'*. Daughter who rang to complain about her mother's care at a clinic. *'They could also ring sometimes and talk. She said you're welcome to ring again. But many times its difficult to pick up the phone . . . you feel you're being a nuisance . . . So perhaps*	handle her mother's illness explained, *'I feel that I was helped. I got to talk with someone and afterwards I felt calmer, I could go to bed and I could sleep.'*

Table 2 continued

	Equal access	Enhanced awareness of — self or — others	Encourage action	Enable action
			they could ring and ask 'How are you doing, would you like to talk?' An older woman who lived alone and rang to find out about how she could get in touch with other people in a similar situation to her own.	
Voluntary representatives as call operators	The interview data revealed that all the representatives from voluntary organisations who acted as call-centre operators felt that they were taken seriously and their views were respected. For example, one voluntary representative explained: *'We feel we've been really involved in everything. We've got information about everything that's happening in the project and they've really turned to us and asked us what we think.'*	Self awareness Both professionals and voluntary workers explained that their work had been affirming in that it had helped them to appreciate their skills as a good listener. A voluntary worker explained: *'I realise I'm sensitive to how people are. I can hear from people's voices how they're feeling. It's something I feel I've been more aware of when people have rung in and I've listened and responded to them.'*	Several voluntary workers explained that their experience of working as a call operator enabled them to see the gaps in public services for older people. In particular, the need to actively listen to older people and their family carers, and promote their needs with other practitioners: *'You shouldn't have to be on death's door to get a place in a nursing home. It's really hard today to get in, it's almost a fight . . . they [Needs Assessors] aren't really prepared to listen, they don't try to bring about*	The interview data with the call operators highlighted that several of the voluntary workers considered they had gained new knowledge, skills and ideas that they could use in their organisation in the future. For example, a voluntary worker explained: *'I feel I can play a larger role and I feel I can make use of what I've learned perhaps more than I think I can. What I feel spontaneously is that I've learnt an awful lot about what's on the web pages (the IC's website), what contacts, networks there are, contact persons in the different*

Table 2 continued

	Equal access	Enhanced awareness of — self or — others	Encourage action	Enable action
			a good meeting even though they come with a negative decision.'	*municipalities, so if someone asks me I know that.'*
Practitioners as call operators	The interview data also revealed that practitioners who worked as call-centre operators felt that they were actively listened to. As one practitioner openly stated: 'I feel that it's been very easy to talk and express my views and if we've had questions or queries it's been easy to get in touch with X [project co-ordinator].'	Awareness of other groups. The interview data highlighted that many practitioners felt that they had learnt a great deal about the role of the voluntary organisations because they'd worked directly with them at the IC. As one practitioner explained: "It's been useful to see who they are, what they're doing and that they in fact serve quite a big purpose. When you get to meet them in person it gives you so much more than just reading about them, because it gives you the opportunity to ask questions directly to them . . .'	Many practitioners voiced surprise and sadness at the degree of loneliness experienced by older people who rang to the IC and felt that this was an important area for further work, not only at the IC but also more generally in society: 'They're many who ring who're lonely they don't have any friends, no relatives, they sit alone, perhaps don't get out. But when it comes to the crunch they don't venture to make contact.'	*The interview data with the call operators highlighted that many of the practitioners also felt that they had gained a lot of knowledge that they could take back with them and use in everyday practice.* *For example:* *'I feel that the knowledge I've got during this time I'll always have use for. When I go back to my usual job full time I can make use of it there. I've got a lot of telephone skills. And I feel I'm able to help with a lot of questions [from work colleagues]* without them necessarily having to run and chase a Needs Assessor. Because I'm available anyway so perhaps they can ask me and I have that knowledge.'

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the more traditional research paradigms, in which the outside researcher largely determines the questions asked, the tools employed, the intervention developed, and the kind of results documented and valued.

(Holstein and Minkler, 2003)

Our experience would suggest that the ÄVS model has considerable potential. It has been developed and refined over a 10-year period between the University College Borås and the School of Nursing and Midwifery at the University of Sheffield. In addition to researchers, this work has actively engaged a range of stakeholders, including practitioners, lobbying organisations and, most importantly, older people and their carers as key participants. As the global challenges facing society become clearer, more informed dialogue and closer partnerships between all interest groups will become increasingly essential if research is to assist us to identify shared solutions to common problems. We would suggest that the ÄVS model offers a way forward by better ensuring that all stakeholders can not only access knowledge, but play a legitimate and important part in its production, use, evaluation and dissemination.

Key points
- Greater involvement of users, carers and service providers in the design, delivery and evaluation of supporting services for older people is now widely promoted.
- To achieve a genuine partnership between researchers and the above group means acknowledging the importance of differing forms of 'evidence' and expertise.
- This raises fundamental challenges about power relationships in the conduct of research.
- Valuing all forms of knowledge promotes opportunities to establish new ways of creating shared understanding between diverse groups.

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