SYSTEMATIC REVIEW

Involving older people in health research

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Abstract

Background: it is a UK policy requirement to involve patients and the public in health research as active partners.
Objective: we reviewed published reports of studies which involved older people in commissioning, prioritising, designing, conducting or disseminating research.
Search strategy and selection criteria: systematic searches of databases (PubMed, SCI-EXPANDED, SSCI, A&HCI, ASSIA, Embase, CINAHL and Medline) for English language studies published between 1995 and 2005 which had involved older people as partners in the research process as opposed to research subjects. Articles were reviewed by two authors using a standardised matrix for data extraction.
Results: thirty studies were included and classified according to the stage in the research process in which older people were involved. Barriers to involving older people were: cultural divisions, language barriers, research skills capacity, ill health, time and resources. Four of the studies had been formally evaluated to identify the impact of involvement. Evaluation focussed on the impact on participants rather than on impact on research processes and outcomes. Benefits to participants included: increased knowledge, awareness and confidence, meeting others in similar situations, empowering older people to become active in their community regarding decisions/policies which affect them.
Conclusions: factors hindering the involvement of older people in research were the same as reported factors hindering involvement of younger people, suggesting that age, per se, is not a barrier. To demonstrate the impact of user involvement on research quality, the definition of user involvement requires clarification, and systematic evaluation of research involving older people needs to be developed.

Keywords: *user involvement, consumer participation, research, elderly, older people, systematic review*

Introduction

The involvement of patients and the public in research has had a long history in fields such as disability, mental health, HIV/AIDS, breast cancer and environmental health [1]. Dissatisfaction with the way research represents patient groups or with the lack of research into areas deemed important, has driven activists to demand a role and a say in how research is conducted [1]. Over the past decade, UK government policy has formalised and promoted this activity under the umbrella term 'user involvement' [2]. The involvement of patients, carers and the public is at the heart of the National Health Service [3, 4] and it is a policy requirement for researchers to consult and involve service users in research [5].

Involve the Department of Health funded body to promote the involvement of patients and the public in health and social care research, define user involvement as 'an active partnership between the public and researchers in the research process, rather than the use of people as the "subjects" of research' [6]. Policy documents suggest that involvement leads to research of greater relevance to people, findings which are more likely to be implemented [5, 6] and empowerment of patients and the public [4]. However, a number of reviews have argued that there is little evidence of the impact of involvement on research processes and outcomes [7, 8].

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Some authors have argued that older people are less consumer oriented than younger people, lack the skills to participate or do not necessarily want to be actively involved in research and developing services [9]. Others have commented on the low priority afforded to involving older people in the planning and development of health services [10] and the under-representation of older people as subjects of research in research studies and trials [11, 12]. The purpose of this review is to establish the scope and extent of the involvement of older people in health research over the past 10 years, to identify reported barriers to the involvement of older people in research and to determine the impact of the involvement of older people on research and on participants.

Methods

We searched English language articles published between 1995 and 2005 using the following databases: PubMed, SCI-EXPANDED, SSCI, A&HCI, Applied Social Sciences Index and Abstracts, Embase, CINAHL and Medline. The search strategy used MeSH and free text terminology combining terms for user involvement (involvement, participation, collaboration, consultation, consumer, user, patient, stakeholder, public, lay) with terms describing research (research, public health, medical research, research agenda, research priorities, research programs, research questions, research methods, participatory research, action research, advisory groups) and older people (older people, geriatric, elderly people). We also searched the bibliographic references of the full-text articles included in the review for further relevant material.

Articles were included if they reported involving older people at any stage of the research process (from commissioning or prioritising research through to the design, conduct and dissemination of research) other than as research subjects. 'Older people' were defined as those over 65 years of age, unless authors defined older people according to different age bands. Where authors did not specify an age, author-defined terms such as 'older people' were used.

We did not use a quality checklist to determine which papers should be included in the review. While this is the usual method for systematic reviews, the approach was not applicable in our case because there is no agreed definition of quality in research projects involving participants. We used Involve's definition of user involvement to determine studies which had actively involved participants: 'doing research "with" or "by" the public, rather than "to", "about" or "for" the public' [6]. In addition, our search was limited to the peer-reviewed literature as this is an accepted indication of quality.

We excluded from the review: exclusively theoretical articles and literature reviews although these were used to inform the analysis and discussion; studies describing the involvement of older people in health promotion activities/interventions, personal/individualised care plans and development of health services; studies that did not specify the ages of people involved; or studies which did not specifically involve older people.

A structured assessment of each article was undertaken to identify: age of users, types of users, degree of involvement in different stages of the research process, roles and tasks undertaken by the older people, barriers to and facilitators of involvement of older people, evidence of evaluation and impact.

Results

Of 2,492 citations initially identified, 35 articles (reporting 30 studies) met the inclusion criteria (see Figure 1) [13–47].

Eleven of the 30 studies originated from the United Kingdom [18, **19, 24, 25, 27, 30, 33, 34, 36, 40, 45, 46**], nine from the USA [13, **16, 17**, 26, **29, 35**, 38, **39, 41**, 42], seven from Canada [14, **15, 20**–22, **31**, 32, 37, 43, 47], one from Australia [23], one from Ireland [**28**] and one from the Netherlands [44].

Of the 30 studies, 10 involved older people in researching health services, looking at aspects such as: equity of, use of and access to services [**16, 17**, 37, **45, 46**]; service evaluation [**41**, 44, 47]; and research to improve and develop services [**33**]. Eleven studies involved older people in research focussing on specific health areas: chronic conditions [**31**]; falls [**15, 36**]; healthy eating [**39**]; mental health [26]; stroke [**27**]; cancer [43]; diabetes [38]; and older people's health in general [13, 18, **19, 29**]. Three studies were concerned with research on health needs assessments [**20**–22, **24, 25**], three with quality of life [14, 23, **34**] and three with assistive technologies [**28, 30, 40**].

We present the data in three sections: the stage of the research process within which older people were involved; factors which facilitate or act as barriers to involving older people; and the impact of involving older people in research. Given that user involvement is promoted through the UK Department of Health policy, Table 1 focuses on the UK literature, describing in greater detail how older people have been involved and the impact of their involvement.

Involvement of older people in the research process

Training

Two studies report older people involved in research training programmes to enable them to participate in research activities [13, 18, **19**, 42]. As part of the training, older people took part in research projects which involved them in interviewing their peers.

Design

Nine studies report the involvement of older people in the preliminary stages of a research study [23, **27, 29, 30**, 37, 38, **40, 41**, 44]. Examples of older people involved in the design of research studies are: understanding concepts such as 'quality of life' and 'quality of care' from the perspective of the older person to develop appropriate research tools [23, 44]; determining the acceptability of a randomised control trial for acute stroke treatment [**27**]; or consultation as part

Table 1. UK literature

Study	Research question/objective	Participants	Tasks of participants	Reported evaluation and impact
Dewar 2003, 2005 [18, **19**]	Research training courses for older people	Thirty participants aged 50+	• Taking part in training courses	Evaluation by informal discussion and questionnaire. Participants reported: increased confidence; listening skills; awareness of social and political issues; ability to 'confront situations' Training encouraged participants to undertake other activities including: working with policy makers and researchers to prioritise mental health research agenda; interview older people; develop research proposals
Horne 2003 [**24**]	To elicit the health needs of older people in East Lancashire	Twelve participants	• Identify health needs	No evaluation reported
Iliffe 2004 [**25**]	To identify unmet needs among older people	2, 3 (?) participants recruited from local voluntary groups	• Develop postal questionnaire • Facilitate focus groups • Participate in consensus conference	No evaluation reported
Koops 2002 [**27**]	To involve older people in designing information leaflets to improve recruitment and consent procedures in a randomised controlled trail (RCT) for thrombolysis	Fifty four participants (consultation meetings); 19 participants (focus groups); 6 carers and patients from a stroke unit (comment on information leaflets)	• Attend consultation meetings • Review information leaflet	No evaluation reported, but authors report that user involvement led to ethical committee approval of the RCT
Marquis-Faulkes 2005 [**30**]	To develop technology to detect falls in older people	Three focus groups: frail elderly group (aged 70s and 80s); mixed elderly group (aged 65+); retired professionals (aged 75–87)	• View dramatised scenarios based on technical possibilities of the system and discussing these	No evaluation reported
Reed 2002 [**33**]	What developments have taken place in discharge planning in the locality? To explore ways of improving the experience of going home from hospital	One older person was a member of the project team. Other participants' involvement not clear	• Initiate idea for research study • Interview older people • Analyse data • Write/edit reports • Co-author journal article	No evaluation reported
Reed 2004 [**34**]	What issues do older people feel most affects their quality of life in retirement?	One participant	• Initiate research question • Interview older people	No evaluation reported
Ross 2005 [**36**]	To explore older people's expectations, priorities and needs for information in relation to risk of falls To compare views of older people on risk factors and risk reduction with those of carers and practioners To inform local implementation of Standard 6 of the National Service Framework for Older People	Twenty one older people formed the 'consumer panel'	• Designing and managing the project • Analysing data • Disseminating study results	Questionnaire to professionals and users to investigate expectations and impact: • Personal benefit of involvement for older people (e.g. opportunity to learn about falls) • Older people enabled to offer a different perspective to the research

Table 1. (*Continued*)

Study	Research question/objective	Participants	Tasks of participants	Reported evaluation and impact
Seale 2002 [40]	To identify and describe nature of indoor mobility related problems and technological solutions to these To propose further research and development of technological products To obtain older people's responses to these proposals	Thirty seven participants aged 70+; 21 participants aged 80+	• Participate in focus groups answering three questions determined by the researchers	No evaluation reported but users identified issues not anticipated by researchers and proposed solutions to problems
Tetley 2003 [45]	To explore older people's involvement in decision making	Seven participants as part of an advisory committee	Advise on project—no further details. The focus of article is to describe experiences of involvement	No evaluation reported. Anecdotal evidence of the impact: advice helped researchers to work effectively and positively with different community groups; users benefited socially
Warren 2003 [46]	To examine the experiences of women over 50 from a range of ethnic groups on use of health services	Ten female participants	• Interview older women • Identify themes from interview data • Publicise findings	No evaluation reported. The authors report anecdotal evidence of impact on participants: feeling valued, validated and important; building confidence and motivation

of the process of seeking approval for research projects by indigenous community groups [29]. In all cases the research question remained unchanged after consultation with older people, with the exception of the study on indigenous health where a more appropriate research question was developed after input from an indigenous older person [29]. Focus groups were predominantly used to elicit older people's views on the topics concerned.

Data collection and data analysis

Three studies report the involvement of older people in data collection and data analysis [24, 43, 46]: conducting interviews, identifying and discussing emergent themes in content analysis of qualitative data and publicising findings.

Advisory groups

Nine studies involved older people in the research through an advisory group [14, 16, 17, 26, 31, 32, 36, 39, 45, 47]. The principle of the advisory group is to oversee the running of the research project usually from the outset through to the completion of the research. In four cases, as people became more involved in the research, they assumed a more active research role including identifying and discussing emergent themes in qualitative data and interpreting, disseminating and implementing research findings [14, 17, 31, 36].

Project definition to project completion

Seven studies report older people actively conducting research throughout the entire research process: defining

the research questions, collecting data, analysing data and disseminating and publicising the findings [15, 20–22, 25, 28, 33–35]. In all the cases, the research was initiated and led by researchers from university departments.

In two of the studies [21, 35] advisory groups of older people were also established in addition to the research team to oversee and contribute to the running of the project and as 'one way to shift more control' of the research to the older people involved [21].

Barriers and facilitators of involvement

Tables 2 and 3 respectively, list the factors which hindered or helped the involvement of older people in research. Eleven studies did not report any facilitator or barriers [14, 23, 24, 25, 26, 32, 37, 38, 42–44, 47].

Impact

Only four studies undertook a formal evaluation of involving older people in the research studies [17, 18, 19, 20–22, 36]. Authors of 23 studies commented on the impact of involvement using anecdotal evidence from their experience of involving older people in research. One of these authors acknowledged that formal evaluation was needed [13]. Three studies did not comment on the impact of involvement [37, 43, 44].

Formal evaluation

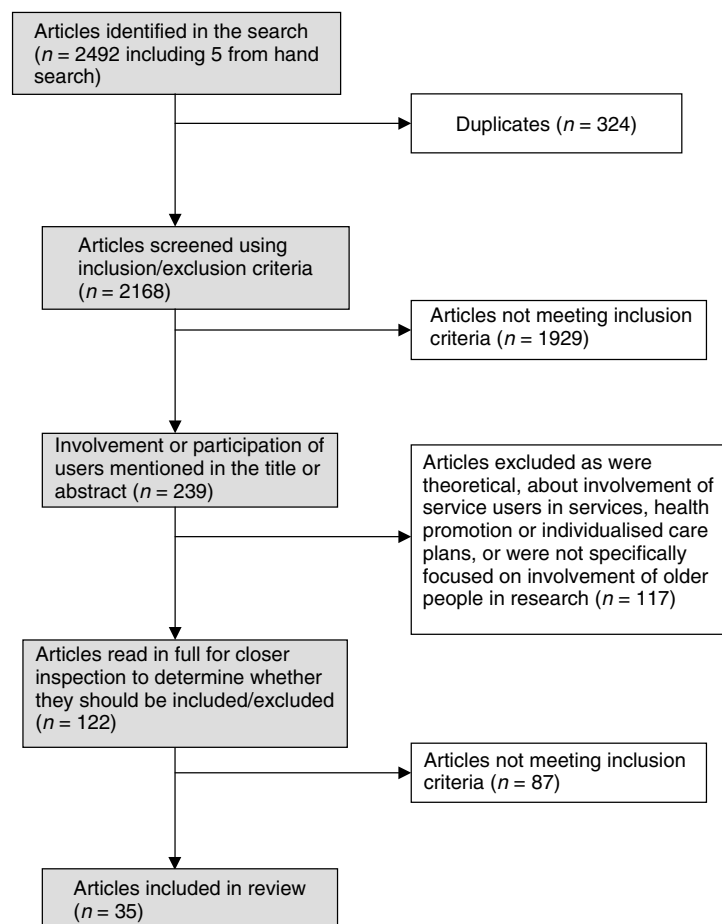Formal evaluation focused primarily on the process of involving older people, using questionnaires or focus group

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Figure 1. Flowchart of literature search and article selection.

discussions to identify 'top tips' for involving older people in research [36] or to determine the levels of satisfaction of taking part in such a process [17]. One study that evaluated training courses through informal discussions and questionnaires demonstrated the impact of involvement on participants [19]. This included: 'developing a more critical approach; increased confidence, learning to listen to others' points of view; increased awareness of social and political issues; increased ability to confront situations; learning that we are not alone' [19]. Dewar [19] suggests that the impact of training older people in research can be demonstrated by the kinds of activities older people, having completed the course, are now involved in: working with university researchers to develop research proposals and prioritise the mental health research agenda; and interviewing older people for a research project on healthy eating.

Dickson [20] conducted the most comprehensive evaluation using an ethnographic approach. This involved in-depth interviews with 14 of the 25 older women involved in the research and participant observation to determine the impact of involvement on the participants.

There is little evaluation focusing on how involvement has changed the research process or research outcomes although two authors report that involvement in research encouraged participants to become active in their community

on issues of relevance to them [19, 20]. However, Dickson [22] also reported that the participants' capacity to act as co-researchers was limited by resistance to having to commit to regular meetings of a business or political nature; poor health; unease with working in English or using translators; or unfamiliarity with expressing opinions and beliefs. Part of the evaluation questionnaire used in Ross *et al.*'s study [36] assessed the impact of involvement on research from the perspective of those involved. A finding from the questionnaires was that the 'older persons' perspective was seen as essential: 'without the consumers' participation it would not have got off the ground' [36].

Anecdotal evidence

Evidence of impact based on authors' reflections or anecdotal stories placed greater focus than the formal evaluations on the impact of older people's involvement on research processes and outcomes. Involvement has an impact on older people through realisation that they can shape public policy [13, 14, 22, **35, 45**]. Participants' contact with local organisations and advocacy groups helps to canvass further opinion, disseminate findings, raise awareness of the project and implement research findings [22, **31, 35, 36**]. Consultation with older people in the design stages resulted in a number

Table 2. Barriers to involving older people in research

Stage in process of involving older people	Barriers	Studies
Recruitment	Certain ethnic groups feel 'over-researched' and have a negative perception of research, therefore reluctant to participate	Dickson 2001 [21]; Dickson 2001 [22]; Warren 2003 [46]
Sustaining involvement	Lack of suitable venues: not everyone feels comfortable in religious venues	Warren 2003 [46]
	In-house caterers not providing adequate or culturally appropriate food	Warren 2003 [46]
	People with hearing problems excluded, despite best efforts	Warren 2003 [46]
	Power imbalances—tension, conflicts between users and researchers	McWilliam 1997 [31]; Reed 2004 [34]
	Service users belief that they cannot make a difference and that nothing will change despite the research occurring	Cockburn 2002 [15]; Reed 2002 [33]; Warren 2003 [46]
	The lack of participation by senior decision makers created tension as the project was not seen to be valued by those who ultimately make the decisions	Reed 2002 [33]
Carrying out research activities	Lack of confidence, unfamiliarity with research	Dewar 2005 [19]; Dickson 2001 [21]; Reed 2002 [33]; Warren 2003 [46]
	Ill health, multiple medical conditions, hospital appointments, physical frailty and death meant that users were not always able to complete research tasks	Delgado 1996 [17]; Lacey 2000 [28]; Dickson 2001 [22]; McWilliam 1997 [31]
	Communication: language barriers, jargon	Cockburn 2002 [15]; Dickson 2001 [22]; McWilliam 1997 [31]; Ross 2005 [36]
	Tension between users and researchers as to what constitutes a good study or what the purpose of research is—differences between knowledge, experience, researcher/user priorities for the study outcomes and expectations of the research donors	Dickson 2001 [22]; Reed 2002 [33]; Roe 1995 [35]; Ross 2005 [36];
	Time—older people have other commitments contrary to belief that older people's time is widely available	Cockburn 2002 [15]; Reed 2004 [34]
	Time—user involvement can significantly alter the research timetable	Roe 1995 [35]; Warren 2003 [46]
	Researchers underestimated people's desire to be more actively involved	Warren 2003 [46]
	Researchers overestimate people's capacity to be active co-researchers	Dickson 2001 [22]; Reed 2002 [33]
	Resources for user involvement and the need for funding underestimated	Warren 2003 [46]

of positive outcomes: one study was accepted by an ethics committee [27] and another by an indigenous community board [29]. Consultation also led to a more salient study design [39], resulted in discussion of issues researchers would not have anticipated [40], achieved better recruitment rates [17] and facilitated the consent process [27, 45].

Authors of studies that did not undertake a formal evaluation also suggested that participants' involvement led to: increased knowledge, awareness and confidence; meeting other people in similar situations; and the therapeutic value of being 'listened to' [17, 20–22, 27, 30, 36, 45].

Discussion

This review has shown that examples exist of older people who have been involved in research beyond providing data for research. Older people tended to be involved in health areas or services specific to older people: stroke; falls; assistive technology associated with decreased mobility; and quality of life as people age. The articles reviewed were published across a broad spread of journals although gerontology and nursing journals dominated.

The involvement of older people in research appears to be a growing phenomenon based on the increasing number of publications each year over the 10-year period reviewed. The growth in recent years was particularly evident in the 11 articles from the United Kingdom, which were all published between 2002 and 2005. The apparent increase is perhaps an artefact of user involvement being topical and therefore publishable but it may also reflect the response of researchers to requests from government and donors to involve participants in the research. The effect of this policy requirement may be further demonstrated by the fact that in almost all the studies reviewed the request for involvement was initiated by university researchers rather than patients demanding to have a role in what is researched and how it is researched.

Our review identified a number of barriers to involving older people in research: cultural divisions; language barriers;

Table 3. Factors facilitating involvement of older people in research

Stage in process of involving older people	Facilitators	Studies
Recruitment	Culture brokers/community guides/personal contacts for recruitment	Crist 2003 [16]; Delgado 1996 [17]; Manson 2004 [29]; Shellman 2000 [41]; Warren 2003 [46]
	People interested in joining the study if involvement would be worthwhile and research findings would result in change (e.g. in health services, health policy, health inequalities)	Dickson 2000 [20]; Manson 2004 [29]; Ross 2005 [36]; Warren 2003 [46]
	Older people already involved recruiting others to be involved	Crist 2003 [16]
Sustaining involvement	Personal connections to sustain involvement and remind people of their part in a collaborative group (e.g. 'thank you' notes, telephone calls, Christmas cards, social mornings, newsletter)	Crist 2003 [16]; Dickson 2000 [20]; Roe 1995 [35]; Ross 2005 [36]; Warren 2003 [46]
	Flexibility of agenda—allowing other issues (outside of the research agenda) to come up and be discussed	Crist 2003 [16]; Dickson 2001 [22]; **Ross 2005** [36]; Warren 2003 [46]
	Time to build up partnerships and trust	Dickson 2001 [22]; Warren 2003 [46]
	Commitment and support of the research team to mediate cross-cultural and power imbalances	Cockburn 2002 [15]; Dickson 2001 [22]; **Ross 2005** [36]
	Training, information, orientation and welcome package	Cockburn 2002 [15]
	Ownership—users as chair, university researchers not the sole expert role	**Ross 2005** [36]; Saunders 2003 [39]
	What older people get out of being involved—knowledge, sociable aspect, lunch, enjoyment, self-healing/therapeutic value, increasing confidence	Delgado 1996 [17]; Dickson 2000 [20]; Koops 2002 [27]; Marquis-Faulkes 2005 [30]; **Ross 2005** [36]; Tetley 2003 [45]
	Suitable venues: e.g. accessible for people with disabilities, places people meet on 'own terms', research departments—people liked attending places that are 'usually off-bounds to community groups'	Delgado 1996 [17]; Saunders 2003 [39]; Warren 2003 [46];
	Reciprocity—researchers also giving something back to community they are working in, e.g. researchers providing information on social services	Crist 2003 [16]; Delgado 1996 [17]; Roe 1995 [35]
Carrying out research activities	People welcome the chance to discuss medical and health issues	Koops 2002 [27]; Tetley 2003 [45]
	Focus groups and dramatisation to stimulate discussions	Marquis-Faulkes 2005 [30]
	Focus groups allowed discussion of issues not anticipated by researcher, which were then incorporated in research design	Seale 2002 [40]
	Allowing users rather than 'experts' to define the research problem to encourage ownership and participation in the research	Dickson 2001 [22]; Roe 1995 [35]

research skills capacity; ill health; time and resources. These barriers do not differ from barriers identified from studies involving younger people [48, 49].

Benefit for research of user involvement

Increasingly in the UK, donors and ethics committees ask researchers to state how they will involve patients and the public in the research process, yet there has been little critical discussion of the reasons for promoting involvement with the general assumption that this is a 'good thing' [50]. Although policy documents justify involvement as a way of improving research and making research outcomes more relevant for

the end-users of research, there was little evidence from our review that this has been achieved. This was because very few of the studies undertook any formal evaluation. Where evaluation was undertaken, this focussed mainly on the processes of recruiting and involving older people, or the impact of involvement on participants.

A common outcome of involving older people was the increased political engagement and confidence of older people to critique policies relevant to them. The older people involved often had contacts with relevant organisations which could help to publicise or implement the research findings [16, 31, 36, 45]. A number of the authors commented

that participants were motivated to be involved because they wanted something (e.g. a service, a policy) to change as a result of the research [14, **20, 36, 46**]: they did not want to be involved in research for the sake of doing research. Being involved in the research enabled or empowered them to feel that they could make this change.

The empowerment of users is promoted as one of the benefits of involving older people, or patients and the public in general, in research [51]. There are many definitions of empowerment. Cheater [52] distinguishes between empowerment defined as access to resources and as a right to express an opinion. It is the latter definition that those promoting user involvement on the basis of empowerment refer to. However, those promoting empowerment through user involvement have yet to demonstrate how user involvement empowers people equitably. A number of the articles reviewed commented on how difficult it was to reach certain groups [22, **41, 46**]. None of the articles in the review reported in detail who the users were, nor did they address the question of representation. The fact that older people in a number of the studies reviewed were able to publicise the research project and findings within their own networks, and advocacy groups suggests that those who decide to participate are those who are already engaged and are, perhaps, the group which needs empowering the least.

Defining user involvement

In undertaking this review, we found that involving people in research can be interpreted in many ways. We used a specific definition of involvement: older people involved in a way that went beyond being subjects of the research. However, for many researchers, involvement meant having participants complete a questionnaire or take part in an interview, particularly if the data involved research subjects' opinions or perspectives. Some of the articles excluded from the review seemed promising from the terminology of involvement used in the title, abstract and introduction, yet upon reading the article in full, no example of actual involvement, beyond older people providing data as research subjects, was reported.

This is a problem caused in part by the lack of definition of user involvement and the myriad of terms used to describe involvement activities: participatory research, collaborative research, user involvement, consumer involvement, participatory action research. It may also highlight the problem of user involvement, promoted as an unclear policy that researchers are expected to undertake. Lack of an agreed definition and clear policy may lead to tokenistic involvement and permit spurious claims of user involvement by researchers to meet and fulfil funding and research ethics committees' requirements [50].

The promotion of an unclear policy further highlights the need to fully understand the impact of user involvement on research. If it can be shown that the involvement of older people (or other population groups) can enhance both research processes and outcomes, researchers may be less inclined to treat user involvement as something they have to do and instead, undertake genuine engagement with older people.

None of the articles reviewed described any failure of involving older people in research although the difficulty of involving users as researchers is acknowledged. This could be a publishing bias: that articles containing negative results are not written or published. It may also relate to the lack of agreed definition and outcomes of user involvement.

Limits of the review

Our review only included studies that involved older people; studies may exist where older people have been involved in research along with younger people. We may also have inadvertently missed studies that may have involved patients or the public, for example, on a project advisory group, but not reported this in their publication of the research. Our study is further limited by restricting our searches to peer reviewed journals. The grey literature, including books and the Internet, may provide additional information about studies that have involved older people.

Conclusion

This review demonstrates that the involvement of older people in research is a growing phenomenon: particularly in the United Kingdom. The barriers to involving older people identified were similar to barriers identified in other reviews or studies involving other patient groups, suggesting that it is not necessarily harder to involve older people simply because of their age. Furthermore, anecdotal evidence from the articles reviewed suggests that older people are interested in research, particularly if it is a means to becoming politically active and aware and the research findings change services or policies.

As other reviews of user involvement have concluded, very little is known about how involvement changes the research process [**7, 8**]. Very few studies in the review performed any formal evaluation. Where evaluations were conducted they tended to focus on the benefits of involvement to those who participated in the research rather than on the benefits for research questions, processes and outcomes. This should be addressed before user involvement is further promoted as a policy.

Key points

- The involvement of older people in health research is a growing phenomenon, particularly in the United Kingdom.
- Factors hindering the involvement of older people in research are the same as reported factors hindering the involvement of younger people, suggesting that age, per se, is not a barrier.
- However, as very few studies undertook evaluation of involving older people in research very little is known about how involvement changes research process, outcomes and quality.

Conflicts of interest

None declared.

Ethical approval

Not required.

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PLEASE NOTE: The very long list of references supporting this review has meant that only the most important are listed here and are represented by bold type throughout the text. The full list of references is available on the journal website http://www.ageing.oxfordjournals.org/ as appendix 1.

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