**Participation in Voluntary and Community Organisations in the United Kingdom and the Influences on the Self-Management of Long -Term Conditions.**

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**Abstract**

Community and Voluntary Organisations (VCOs) have health benefits for those that attend and are viewed as having the potential to support long-term condition management. However, existing community level understandings of participation do not explain the involvement with VCOs at an individual level, or the nature of support which may elicit health benefits. Framing active participation as “doing and experiencing”, the aim of this qualitative study was to explore why people with long-term vascular conditions join VCOs, maintain their membership and what prevents participation. Twenty participants, self-diagnosed as having Diabetes, Chronic Heart Disease or Chronic Kidney Disease, were purposefully sampled and recruited from a range of VCOs in the North West of England identified from a mapping of local organisations. In semi-structured interviews, we explored the nature of their participation. **Analysis was thematic and iterative involving a continual reflection on the data.** People gave various reasons for joining groups. These included health and well-being, the need for social contact and pursuing a particular hobby. Barriers to participation included temporal and spatial barriers and those associated with group dynamics. Members maintained their membership on the basis of an identity and sense of belonging to the group, developing close relationships within it, and the availability of support and trust. Participants joined community groups often in response to a health related event. Our findings demonstrate the ways in which the social contact associated with continued participation in VCOs are seen as helping with long-term condition management. Interventions designed at improving chronic illness management might usefully consider the role of VCOs.

*Keywords*

Participation; long-term condition management; Voluntary and Community Organisations, Social networks; Social Support

*What is known about this topic*

* Self-management of long-term conditions is shaped by broader social contexts.
* Community participation and community cohesion may have benefits to health.
* Participation in VCOs has been described in terms of working communally, sharing knowledge, and a commitment to collective activity.

*What this paper adds*

* The social aspect of the “doing and experiencing” of participation involves companionship which allows for mutual health support.
* Participants overcame barriers to maintain their membership by taking on meaningful roles and having a sense of ownership of the group.
* Formal health services should have a greater connectivity with VCOs to utilise their resources to support self-management.

**Introduction**

There is an increasing financial burden to health services from caring for those with long-term conditions. This has led to policy makers finding ways to place self-management responsibility with the individual (DoH 2012, DoH 2001) whose lifestyle and behaviour are under scrutiny (Galvin 2002). Many programmes designed to support self-management are based on models of individual behaviour change. Whilst programmes such as the Expert Patient Programme have played a somewhat paradoxical role in increasing social capital through triggering health consumer movements outside the programme (Wilson, 2007), researchers have been critical of an over focus on psychological mechanisms (Vassilev *et al.* 2013, Rogers *et al.* 2009, Kendall & Rogers 2007) such as self-efficacy, as the basis of improving condition management (Marks Allegrante & Lorig 2005, Lorig *et al.* 1999). Self-management is shaped by broader social contexts and involves a broader set of imputed resources relevant to managing a long-term condition well. Voluntary and Community Organisations (VCOs) represent one of these sources of support (Vassilev *et al.* 2013, Kendall & Rogers 2007, Kennedy *et al*. 2007, Campbell & Murray 2004).

Participation in VCOs has been conceptualised in terms of levels of participation, the ways in which participation is facilitated by community development, and through the relationships in communities that are influenced by participation (Heritage & Dooris 2009). Taking part in groups and associations is a predictor of a long life (Dalgard & Haheim 1998) and associated with self-related good health, linked to social capital gain from greater community spirit and empowerment (Hyyppa & Maki 2003). The connection between participation and health can be framed around community capacity-building and associated increases in social capital and community cohesion. Additionally, the benefits for managing long-term conditions might lie in an increased collective activity and generalized trust incorporated within social capital which is predicated on social connectedness relevant to health and well-being (Smith & Christakis 2008, Ferlander 2007, Putnam 2000). Social capital has been linked to reduced mortality and increases in positive self-rated health status (Kawachi *et al.* 1999). This implicates both social support and networks linked to social cohesion, whilst a lack of social support and ability to access community resources, leads to greater social isolation (Campbell & Jovchelovitch 2000). Contexts of “participating with others” may help people, experiencing a long-term condition, both gain control of their existing disrupted lives and envisage a perceived control of their futures (Campbell & Jovchelovitch 2000: 261).

These existing community level understandings of participation do not explain VCOs involvement at an individual level, or the nature of support which may elicit health benefits. Participation in voluntary and community groups has been described in terms of working communally, sharing knowledge and skills, and a commitment to collective activity (Milligan *et al.* 2004). The social engagement gained from community roles and associated opportunities for companionship and sociability instil a sense of value, belonging and attachment that might be achieved through wider social networks (Berkman *et al.* 2000). In this respect the voluntary sector has acted as a source of information, health related resources and delivery of self-management programmes (Kennedy *et al.* 2005). It is, however, through active participation in community groups and the “doing and experiencing”, not merely utilisation, that people have been seen to gain health benefits such as a return to normality (Makin & Gask 2012: 65). More active participation might involve reciprocity of help, mutual aid and support which are health related (Letcher & Perlow 2009).

The reasons why people with chronic illnesses might join have not been fully investigated. VCOs might be rich areas for the development of social capital "where people learn civic skills important for working together co-operatively” (Ziersch & Baum 2004: 493). Broad motivations for volunteering include learning new skills, preparing for a career or expressing personal values and community commitment (Macdonald *et al.* 2009, Thoits & Hewitt 2004). To date there has been little research focused upon people with chronic ill-health. The context of people's involvement and the ways they might join and continue participation of a broad range of community groups has not fully been explored. This study aimed to explore how and why people, with long-term vascular ill-health, join VCOs; what prevents them going to groups; and how they maintain and continue their membership.

**Methods**

This study adopted a qualitative design using semi-structured face-to-face interviews with members of VCOs across the North West of England.

***Sampling and Recruitment***

In a preliminary stage of the study structured telephone interviews were completed (January 2012- May 2012) with leaders of 98 organisations sampled from an existing database of health-relevant and non-health orientated voluntary and community groups (Blickem *et al.* 2013). This convenience sample attempted to reflect a range of groups active in the community including support groups, hobby groups, advice or resource based organisations, and community centres. From the telephone interview data we purposefully sampled (Patton 2002) 33 groups, to include a variety of organisations across the North West of England, and conducted face-to-face semi-structured interviews with the group leaders.

After completing interviews with the organisation leaders (July 2012 – October 2012) and visiting a selection of the groups (November- December 2012), we purposefully sampled organisations, to recruit members to take part in interviews for the current study. The sampling was based on the range of activities the group offered; their health relevant activity; and the number of health and non-health related groups they connected to. Organisations were selected to represent those that were health-related **and** those that did not have explicit ‘health benefits’ (Blickem *et al.* 2013). The researchers visited the selected groups and used flyers to recruit participants. Group leaders helped advertise the study, acting as gatekeepers. The recruitment criteria included participants who: were a member of one or more VCOs and had one or more long-term health condition (Diabetes, CKD and/or CHD).

***The participants***

Twenty participants, self-diagnosed as having Diabetes, Chronic Heart Disease (CHD) or Chronic Kidney Disease (CKD) were recruited from seven different VCOs (see table 1)These were sampled from a selection of those who returned forms to include a maximum variation of participants (see figure 1 and table 2). Twenty participants were interviewed to allow for in-depth exploration within the pragmatics of the resources and time available.

***Data Collection***

Two researchers (AM and MJ) undertook the interviews (February and May 2013).The interviews were held at the participants’ homes or at the groups’ meeting place. The interviews explored the nature of participation in the group; the impact of health on participation; and chronic illness management. An adapted version of the hierarchical mapping technique (Antonucci 1986) was used to reveal the roles of key people who helped with the day-to-day management of their chronic illness. This provided the scope for respondents to talk about social participation in the context of their broader network. Written informed consent was obtained before the interview. Interviews ranged from 39 minutes to 2 hours in length. All interviews were recorded using digital audio equipment and transcribed verbatim. To preserve anonymity pseudonyms were used and names of places omitted.

***Analysis***

Data analysis took place alongside data collection. Field notes and narrative case summaries were written soon after each interview and circulated amongst the research team. These narrative summaries included what was discussed in the interview in relation to the research questions, and any key themes that had emerged (Flick 1998). MJ and AM discussed these and read transcripts to refine data collection and highlight new areas of enquiry (Pope *et al.* 2000). We reflected upon interview transcripts and field notes to move from description of the data to analysis and interpretation (Popay, Rogers & Williams, 1998). Regular meetings were held with all authors to discuss emerging themes and further analysis. As part of this process a thematic framework was generated and applied to the data. Coding was an on-going process involving a continual reflection on the data (Creswell 2003). Broad themes were broken down into sub-themes, new themes emerged and were introduced to unpack the data further, thereby refining the analysis and enhancing the findings. Comparisons were made across cases to identify similarities and differences between participants and the different voluntary group memberships. Atlas ti version 6.1 was used to assist analysis.

***Ethics***

The study was given ethical approval by North West 7 Research Ethics Committee-General Manchester Central reference 10/H1008/1.

**Findings**

**Reasons for Participation**

People gave various reasons for joining groups including improving their health and the need for social contact.

***Pursuing a hobby as a means of connecting to others***

Participants joined to take part in a hobby or interest. For some, this was to have ‘something to do’, often in response to a life event such as retirement or bereavement. Having a hobby was seen as a way to keep occupied. Participants joined groups because they felt that they would have something in common with group members; to learn or share skills and co-operate on activities:

“R: It was the friendliness […] I mean I couldn't sew to save me life but, you know, they said oh well we'll show you […] you know, that's the sort of people they were. Well they were showing me how to do crocheting […] Which, you know, it was...as I say, it was just dead friendly […] it was, you know, they made you feel welcome and it was easy to get on with them”*(Ann, VA10)*

In this example, the group members were encouraging and shared skills, which increased her confidence and developed her self-esteem. Participants joined groups because they liked the camaraderie. Whilst some participants joined to take part in activities, they were also motivated because of the opportunity ‘to have a chat’ and ‘share news and gossip’:

“It’s the friendliness and the feeling that you can say what you want and it doesn’t really matter, not, not rude, but you know, not being nasty at all in any way, but, erm, just, just say what you want, it's so free and easy in a way it's like being a child again, you know, because we have fun and nothing is serious which, which I like.”*(Ingrid,VA09)*

The group provided friendliness and ‘fun’ activities that offered relaxation. There was a sense that groups provided escapism and an opportunity for open conversation. Meeting people at the group offered opportunities for social contact and brought people together:

“I find it difficult to walk very far, yes, but, I like to get out, I've got to be ill before I stop going to the club, I make myself go, because I find that once I do go I'm better for being with people, I need that, you know, contact with people, yes, because, we're in a row, well I live in a row of seven bungalows and we're all elderly or disabled in some way, so of course the same applies to them if the weather’s bad and can't get out, we don't see anybody and they're awful long days.” *(Ingrid, VA09)*

Ingrid described how she was prepared to make the extra effort to go to her club because she saw that she was “better for being with people”. Getting older and declining physical health led to feelings of vulnerability and the risk of isolation. This isolation was seen in terms of long days of not seeing anyone. Participation in the group provided an important opportunity for social contact.

***Participation as a catalyst for change***

Participants joined groups for eliciting specific health benefits linked to fitness and personal health targets relating to illness management. This was sometimes linked to a ‘tipping point’ such as a health event or diagnosis:

“…they do a ten week course, so I’ve…these last ten weeks I’ve been going every, every Tuesday afternoon to weigh in and, and I’m, I’m losing the weight…[…]…to come down to the target that, that they want, so I’m, I’m quite pleased with that, so hopefully, um, diabetes is not going to raise its (head)” *(Neil,VA07)*

Being told by a healthcare professional that he was at risk of developing diabetes motivated Neil to change his lifestyle, join a NHS Lifestyle Service in addition to his health support group, and set personal goals to lose weight. Taking action in terms of joining the group gave him a sense of achievement and control over his health.

Here the group acts as a respite and release from the difficulties faced in living with a long-term condition and gives the participant the opportunity to ‘have a bit of a laugh’ and ‘takes his mind off it.’:

“… you feel that you’re a burden, and because patience has never been me strongest point, and now I’m…it’s even worse, , there’s a tendency to snap […] at your family, I […] that’s worse than having a row and I find then like when we’re going to the group I, I switched off from all this and I’m going and have a bit of a laugh and, and fun, and yesterday we had the, er, a chap coming and, and singing folk songs and what-have-you […] and, your mind’s taken off the day ” *(Neil, VA07)*

**Barriers to Participation**

Although the participants in this study were active members of VCOs, there was a recurring theme around the barriers to participating.

***Temporal and Spatial Barriers***

Members’ commitments and responsibilities outside the group were identified as a potential barrier to participation. Participants told how other commitments such as work, hospital appointments or family responsibilities reduced their level of involvement. One participant in full-time employment compared himself to retired members who had more investment in the group and socialised beyond it. He predicted that on retirement, his level of involvement would increase and he would have the time to join another group:

“I suppose probably if I was retired or something I may, erm…I think there’s a couple of chaps there they, they meet up, then I’ve got a … [name] I’m quite friendly with he, he’s retired […] yes, erm, I suppose probably if I was retired I would probably spend a bit more time you know with some of them.” *(Michael, VM32)*

Participants experienced difficulties accessing groups because of location and articulated the need for their own transport to attend group sessions and social events:

“You do need a…well I know some people don’t, but it does limit you what you can do without a car […] So you really need a car or live near somebody that can give you a lift, which…unfortunately I don’t. There’s nobody round here that belongs to [the group].” *(Joyce,VM26)*

Participants who did not have a car were dependent upon other members; public or community transport; and taxi services. In some cases, these means of transport were described as ‘hit and miss’:

“It's based in (*name of city*) now and the people that operate the service they don't realise how long it takes to get from A to B. Where the people that were local to [name of town] they knew, so the pickups are a bit hit and miss at times, you know,it's not really I mean I wouldn't trust them to take me for a hospital appointment or anything like that, you see, because it's not, not smack on the time you want…” *(Ingrid, VA09)*

For this participant, community transport was seen as untrustworthy and a service she could no longer rely upon. Similarly, taxis were believed to an expensive alternative that were not always viable:

“It's like I can't get a taxi to [name of road] 'cos the taxi driver wouldn't just take you that short distance […] It's not worth it, by the time they've drove here and they're getting nothing more or less, I'm going five minutes down the road.” *(Ann,VA10)*

***Group Dynamics***

Participants required groups to be accommodating, cater to their health needs, and welcome new members. Group leaders and volunteers established relationships with members to encourage involvement and create an inclusive environment. Participants described a sense of the group leaders monitoring their health and felt ‘in safe hands’.

Participants described groups they had previously attended which were not seen as welcoming, where they were unable to comfortably participate or develop friendships. Cliques within groups acted as barriers to participation and members discussed ideally having a cohesive group, participating in activities together. Similarly, participants articulated their fears associated with attending a group alone:

“And I said well, you know, I don't like going to places on me own...I said, you know, it's a bit horrible walking in and because I'd spent that long on me own I just didn't have the confidence to walk into strange places. I mean I'm alright once I'm there and if somebody talks to me but if you're totally ignored or anything. You know, you wouldn't go back again.” *(Ann, VA10)*

The activities and services offered by the group, could act as a barrier if they failed to meet participants’ expectations. Prior to joining, participants were aware of their needs and what they wanted from their membership. One participant, after attending taster sessions, decided to become a member of another group as the activities were more ‘akin to [his] needs’:

“[…] I just, um [name of group] do a lot of activities that I’m not struck on. Well they do a lot of handy crafts and things like that, and I, I’m not, I’m not keen on, on, um, doing…and having met the people who, who are, …run it, I’m not…it’s just some…something about it doesn’t draw me […] I decided I’d join the [name of town] group ‘cos that, er, felt more, akin to my needs…” *(Neil, VA07)*

These ‘needs’, referred to a space in which he could discuss health concerns, and long-term condition experiences. Not all groups offered this support however, and participants discussed feeling uncomfortable sharing problems and asking other members for advice. This was attributed to the group being too large to have these discussions:

“No, it’s…you see there’s the British Heart Foundation group, but…you meet once a month and not everybody goes every week, and although they have lectures by cardiologists there are so many of us at the meetings that you don’t feel you can say can I talk to you about my problem.” *(Agnes, VM26)*

Although this was not a reason to withdraw from the group, some participants were disappointed when groups did not offer this support. This could be attributed to a lack of regular contact with people. In this way the group dynamics acted as a further barrier.

**Maintaining membership**

People embedded their participation in groups where they had a sense of ownership. Continued involvement with the group was enhanced by the support it was perceived as offering. This was available through feeling bonded to members of the group.

***Embedded Participation and Belonging***

Participants worked to maintain their membership of organisations by deepening their engagement with the group through taking on roles or prioritising their involvement. Here the increased time involved in running this walking group was part of the enjoyment of being a member:

"I: So how do you feel about putting all that extra time in?

R: I love it [...] I mean there has been talk within the group about, some people say they should, we should get, some kind of expenses. [...] just a bit petrol, basically.[...] I mean we recently went to (*name of place*) [...] for a weekend. And I lead a walk there. So me and Michelle drove down to (*name of place*) and did a recce [...] But I look at it as a labour of love." *(Patrick, VM26)*

Participants made adjustments to the activities they did with the group, prioritising specific tasks and areas of interest, in order to maintain their membership. This participant worked to create an alternative meeting venue for the group to avoid losing touch. Maintaining the valued group network was more important than taking part in the group's walking activities:

 "Well obviously I can’t do the walking, and you can be very cut off in a rambling club because you don’t have a club house [...] like a golf club or [...] a tennis club often has a social side. [...] And so I agitated for us to have a place central where a few people went every so often, and the rest of the club could call in or not as they wished, but they’d always know there was somewhere where we could meet. [...] a lot of us have found it very beneficial to keep in touch…" *(Agnes, VM26)*

Participants embedded their participation more permanently when they expressed a sense of belongingand feeling that the group was ‘theirs’; an important part of their life. This ownership was derived from being with people with similar views with whom they had a connection and a bond:

"We’re out there and we’re chatting and laughing and getting wet through and joking and... I mean we have a great time. [...] And it’d, and everybody says, oh I don’t know what I’d do if it finished [...] I think this is why you keep going " *(Patrick, VM26)*

***Involvement and Support***

Receiving support from other members encouraged participants to maintain their membership. People received emotional support from people with the same condition who were perceived to be “in the same boat”:

"It’s a very nice atmosphere I think, it’s not a kind of morbid atmosphere of you know, oh dear me, you know, aren’t we, er, awful, you know, having got this thing, I mean in a sense we’re the survivors, you know, we’ve had heart attacks [laughter] but actually we’ve come through, so, er, it’s a positive atmosphere. So yes, that there’s a kind of useful social function there I think for, er…I mean I’d, I’d recommend it to people of our age very strongly because it, in a sense, it keeps you in touch with things like this, you talk to other people" *(Bernard,VM32)*

Reciprocity and mutual aid were found in being able to offer each other informational support and give advice.

**Discussion**

This study provides an explanation for participation in VCOs at an individual level through the perspective of “doing and experiencing”; exploring why people with long-term conditions join and revealing the health support such membership offers. Previous research looking at participation at a collective or an individual level has not fully explained participation in community groups and the health benefits achieved through it.

Our research reveals people join groups for health reasons and to increase social contact. As a result of their condition, chronically ill persons are at risk of losing self-esteem and self-identity (Charmaz 1983). Social isolation, living a restricted a life and being discredited are major sources of loss of self; the emphasis on self-management for those living with a chronic illness also leads to the burdening of others (Charmaz 1983). Social isolation and living a restricted existence limits the possibilities for positive validation of self, as those living with a chronic illness become aware that they cannot do the things they once valued and enjoyed in the past (Charmaz 1983). The loss of self (Charmaz 1983), experienced by the participants in this study as a result of their illness, may have been overcome by their VCO attendance. Participants joined to pursue a hobby or interest and to take part in something in the company of others. Our findings reveals that VCOs allows opportunities to construct a valued self (Charmaz 1983), by offering alternative hobbies and activities to participate in. Memberships in VCOs can also contribute to individuals’ independence, decreasing social isolation and the burdening of others.

Ziersch and Baum (2003) work on civil society group (CSGs) involvement reveals the complex relation between participation and health benefits suggesting there may be hidden differences between the types of CSGs and support they offer. Our study found differences between groups offering exercise and the others. Groups were seen as a safe place to discuss illness management. This was more significant in hobby and health support groups than exercise groups. NHS lifestyle service members joined and maintained their membership in order to engage in self-management; participation was seen as an hour’s exercise, to maintain fitness. Similar to Makin and Gask (2011), it was important for participants in our study to meet targets and have a sense of moving forward. There appeared to be different motivations for joining and maintaining membership depending on the group, and the self-care needs of the individual; at NHS lifestyle services achieving health goals was important, at hobby groups social contact was important.

Group membership provided participants with a distraction and respite from health concerns. Our analysis reveals a social aspect to community group membership which involved camaraderie and companionship; participants felt they had something in common with other members. These interactions were considered important to the participants who described attending the group in order to maintain ties. This reveals a situating of self-management in everyday contexts similar to Blickem *et al.* (2013). By situating self-management in everyday contexts, individuals are maintaining a ‘normal life’, a symbol of a valued self (Charmaz 1983).

Although there were no obligations to discuss their health with friends in the group, participants engaged in health support and reciprocity was significant. Social comparison, discussing the impact of illness and evaluating their experience by comparing themselves with others, normalised illness and facilitated group affiliation (Rogers *et al*. 2009). As found elsewhere, health promotion within community groups, mutual aid and opportunities for altruism overcame the feeling of powerlessness for those living with a chronic illness, and group membership assisted with social functioning and re-engagement with everyday life after diagnosis of a long-term health condition (Makin & Gask 2011, Campbell & Jovchelovitch 2000). As a result of this mutual support and the ability to help others, the participants in our study felt they had more control over their own health, resisting a loss of self (Charaz 1983). Similar to Letcher & Perlow (2009), members had a shared identity and engagement in the group improved personal resources such as self-esteem, confidence and leadership. Members viewed their participation as an ‘insurance’ policy; giving them confidence that help will be available to them in the future.

This study has expanded the notion of other people in supporting self-care. Members of community groups do ‘emotional work’, comforting other members who are worried or anxious about everyday matters and health concerns (Vassilev *et al.* 2013). Group membership offers companionship and access to wider networks. Individuals call upon these network ties and access other services to assist their self-management. Social networks play an important role in mobilising and deploying resources in the management of chronic conditions (Rogers *et al.* 2011). VCOs are therefore a context in which people self-manage long-term health conditions by sharing resources and through peer support. This finding is consistent with Vassilev *et al.’s* (2013) research that explores the nature of self-management by focusing on illness-relevant relationships and network structural properties. Their research suggests problems of chronic illness go beyond one’s own capacity for managing and support is required for the everyday demands of living with a chronic condition. Often close family and partners provide this support and are involved in the types of work associated with illness management: illness work, everyday work and emotional work (Vassilev *et al.* 2013, Corbin & Strauss 1985). Group members however, contribute to self-care, particularly by providing emotional support and it is suggested that people who are meaningfully engaged in things beyond the family have greater access to health-relevant support such as health information, promotions and interventions (Vassilev *et al.* 2013).

Our research suggests that certain steps can be taken by voluntary and community groups to avoid losing members. Most importantly, members need to be given a sense that it is ‘their group’. Our findings reveal that ownership across all groups was important to maintaining memberships. Volunteering connects individuals to their communities and generates a sense of social obligation (Narushima 2005). Members, who have greater involvement, for example in leading a walk in a walking club, will be more embedded in the group and therefore more likely to continue their involvement. There is a need for spaces that support social contact and active participation, to involve those socially excluded and relieve isolation (Milligan *et al.* 2004). Ziersch *et al.* (2011) suggested individuals are more likely to participate in areas where they already perceive cohesion and a sense of community. Increased levels of participation could also contribute to this sense of community and contribute to the provision of social capital.

VCOs contribute to social cohesion and offer a “space for possible action” (Campbell & Jovchelovitch, 2000:267), and thus might offer an alternative to formal health services. VCOs have a greater impact on social isolation, and are better placed to offer emotional work, support and respite from health concerns through companionship. Formal health services could benefit from continued connectivity with VCOs to utilise these resources and develop interventions. These relationships will become more significant considering community groups are at the centre of the new Health and Care System (DoH, 2012) and with the **UK government** stressing the important role of the third sector in delivering public services (Alcock, 2010).

Whilst our research has revealed the health benefits from the social side of participation in VCOs, future research on chronic illness management might investigate the similarities between formal health services and VCOs, in terms of their ability to set goals, provide a continuity of care and offer the tools to be better self-managers. It would be interesting to explore the ways non-health relevant groups might provide such specific health support. Although we attempted to capture a range of VCOs the nature of the third sector is so diverse (Kendall & Knapp, 1995) to make this difficult. Perhaps a more in-depth approach focusing upon one type of group or a single organisation could have revealed a nuanced understanding of participation and its role in self-management. A further limitation could be that a possible explanation for people’s varying experiences of participation could have been their age or individual social circumstances which may have determined if people had the resources to participate.

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**Competing interests**

The authors declare that they have no competing interests.

**References**

Alcock P. (2010) Building the Big Society: a new policy environment for the third sector in England *Voluntary Sector Review*, 1, 379-89 DOI 10.1332/204080510X538365

Antonucci, T. C. (1986). Hierachical Mapping Technique. *Generations: Journal of American Society on Aging, 10*, 10-12.

Bath, P., & Deeg, D. (2005). Social engagement and health outcomes among older people: introduction to a special section. *Eurpean Journal of Ageing, 2*, 24-30. DOI 10.1007/s10433-005-0019-4

Berkman, L. F., Glass, T., Brissette, I., & Seeman, T. E. (2000). From social integration to health: Durkheim in the new millenium. *Social Science & Medicine, 51*, 843-857. DOI 10.1016/S0277-9536(00)00065-4

Blickem, C., Kennedy, A., Vassilev, I., Morris, R., Brooks, H., Jariwala, P., et al. (2013). Linking people with long-term health conditions to healthy community activities: development of Patient - Led Assessment for Network Support (PLANS). *Health Expectations, 16*, E48-E49. DOI: 10.1111/hex.12088

Campbell, C., & Jovchelovitch, S. (2000). Health, Community & Development: Towards a Social Psychology of Participation. *Journal of Community & Applied Social Psychology, 10*, 1255-1270. DOI: 10.1002/1099-1298(200007/08)

Campbell, C., & Murray, M. (2004). Community Health Psychology: Promoting Analysis and Action for Social Change. *Journal of Health Psychology, 9*, 187. DOI: 10.1177/1359105304040886

Charmaz, K. (1983) Loss of self: a fundamental form of suffering in the chronically ill. *Sociology of Health and Illness, 5* 168-195

Corbin, J., & Strauss, A. (1993). The articulation of work through interaction. *Sociological Quarterley, 34*, 71-83. DOI: 10.1111/j.1533-8525.1993.tb00131.x

Cresswell, J. W. (2003). *Research Design: Qualitative, Quantative and Mixed Methods* (2nd ed.). London: Sage.

Dalgard, O. S., & Haheim, L. L. (1997). Psychosocial risk factors and mortality: A prospective study with special focus on social support, social participation , and locus of control in Norway. *Journal of Epidemiology and Community Health, 52*, 476-481. DOI:10.1136/jech.52.8.476

Department of Health. (2001). *The expert patient: a new approach to chronic disease management in the 21st Century.* London: The Stationery Office.

Department of Health. (2012). *The Mandate: A Mandate from the Goverment to the NHS Comissioning Board: April 2013 to March 2015.* London: The Stationery Office.

Ferlander, S. (2007). The Importance of Different Forms of Social Capital for Health. *Acta Sociolgica, 50*, 115.DOI: 10.1177/0001699307077654

Flick, U. (1998). *An Introduction to Qualitative Research.* London: Sage.

Galvin, R. (2002). Disturbing Notions of Chronic Illness and Individual Responsibility: Towards a Genealogy of Morals. *Health(London), 6*, 107.DOI: 10.1177/136345930200600201

Heritage, Z., & Dooris, M. (2009). Community participation and empowerment in Healthy Cities. *Health Promotion International, 24*, 45-55.DOI: 10.1093/heapro/dap/054

Hyyppa, M., & Maki, J. (2003). Social participation and health in a community rich in stock of social capital. *Health Education Research, 18*, 770-779.DOI: 10.1093/her/cyf044

Kawachi, I., Kennedy, B. P., & Glass, R. (1999). Social Capital and self-rated health: A contextual analysis. *American journal of Public Health, 89*, 1187-1193.

Kendall, E., & Rogers, A. (2007). Extinguishing the social?: State sponsored self-care policy and the Chronic Disease Self-management Programme. *Disability & Society, 22*, 129-143.DOI: 10.1080/09687590601141535

Kendall, J., & Knapp, M. (1995). A loose and baggy monster: boundaries, definition and typologies. In J. Davis Smith, C. Rochester, & R. Hedley, *An Introductory to the Voluntary Sector* (pp. 66-95). London, New York: Routledge.

Kennedy, A., Rogers, A., & C, Gately. (2005). Frome patients to providers: prospects for self-care skills trainers in the National Health Service. *Health & Social Care in the Community, 13*, 431-440 10.1111/j.1365-2524.2005.00568.x

Kennedy, A., Rogers, A., & Crossley, M. (2007). Participation, Roles and the Dynamics of change in a group-delivered self-management course for people with HIV. *Qualitative Health Research, 17*, 744. DOI: 10.1177/1049732307302754

Letcher, A., & Perlow, K. (2009). Community-based participatory research shows how a community initiative creates networks to improve well-being. *American Journal of Preventive Medicine, 37*, 292-299. DOI: 10.1016/j.ampre.2009.08.008

Lorig, K. R., Sobel, D. S., Stewart, J. L., Brown, B. W., Bandura, A., Gonzalez, V. M., et al. (1999). Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: A randomized trial. *Med.care, 37*, 5-14. DOI: 10.1097/00005650-199901000-00003

Macdonald, W. J., Kontopantelis, E., Bower, P. J., Kennedy, A. P., Rogers, A. E., & Reeves, D. (2009). What makes a successful volunteer Expert Patients Programme tutor? Factors predicting satisfaction, productivity and intention to continue tutoring of a new public health workforce in the United Kingdom. *Patient Education Counselling, 75*, 128-134. DOI:10.1016/j.pec.2008.09.024

Makin, S., & Gask, L. (2012). "Getting back to normal":the added value of an art-based programme in promoting "recovery" for common but chronic mental health problems. *Chronic Illness, 8*, 64-75. DOI: 10.1177/1742395311422613

 Marks, R., Allegrante, J. P., & Lorig, K. (2005). A review and synthesis of research evidence for self-efficacy-enhancing interventions for reducing chronic disability: imoplications for health education practice (part II). *Health Promotion Practice, 6*, 148-56. DOI: 10.1177/1524839904266792

Mendes de Leon, C. F., Glass, T. A., & Berkman, L. F. (2003). Social engagement and disabiltiy in a community population of adults: the New haven EPESE. *American Journal of Epidemiology, 157*, 633-642. DOI: 10.1093/aje/kwg028

Milligan, C., Gatrell, A., & Bingley, A. (2004). "Cultivating health": therapeutic landscapes and older people in northern England. *Social Science & Medicine, 58*, 1781-1793. DOI: 10.1016/S0277-9536(03)00397-6

Morrow-Howell, N., Hinterlong, J., Rozario, P. A., & Tang, F. (2003). Effects of volunteering on the well-being of older adults. *Journal of Gerontology, 58*, 137. DOI: 10.1093/geronb/58.3.S137

Narushima, M. (2005). "Payback time": community volunteering among older adults as a transformative mechanism. *Ageing & Society, 25*, 567-584. DOI: [10.1017/S0144686X05003661](http://dx.doi.org/10.1017/S0144686X05003661)

Popay, J., Rogers,A., & Williams. G., (1998) Rationale and Standards for the Systematic Review of Qualitative Literature in Health Services Research. *Qualitative Health Research 8*, 341-350 DOI 10.1177/104973239800800305

Pope, C., Zieblund, S., & Mays, N. (2000). Qualitative research in health care: analysing qualitative data. *British Medical Journal*, *320*, 114-116.

Principi, A., Chiatti, C., Lamura, G., & Frerich, F. (2011). The engagement of older people in civil society organizations. *Educational Gerontology, 38*, 83-106. DOI: 10.1080/03601277.2010.515898

Putnam, R. (2000). *Bowling Alone: The Collapse and Revival of American Community.* New York: Simon Schuster.

Rogers, A., Bury, M., & Kennedy, A. (2009). Rationality, rhetoric and religiosity in health care: The case of England's Expert Patients Programme. *International Journal of Health Services, 39*, 725-747. DOI: 10.2190/HS.39.4.h

Rogers, A., Gately, C., Kennedy, A., and Sanders, C. (2009) ‘Are Some More Equal than Others? Social Comparison in Self-management Skills Training for Long-term Conditions’, Chronic Illness, 5: 305-317

Rogers, A., Vassilev, I., Sanders, C., Kirk, S., Chew-Graham, C., Kennedy, A., et al. (2011). Social networks, work and network based resources for the menagement of long term conditions: a framework and study protocol for developing self-care support. *Implementation Science, 6*, 56. DOI: 10.1186/1748-5908-6-56

Smith, K. P., & Christakis, N. A. (2008). Social Networks And Health. *Annual Review of Sociology, 34*, 405-29. DOI: 10.1146/annurev.soc.34.040507.134601

Thoits, P. A., & Hewitt, L. N. (2001). Volunteer work and well being. *Journal of Health and Social Behaviour, 42*, 115-131.

Vassilev, I., Rogers, A., Blickem, C., Brooks, H., Kapadia, D., Kennedy, A., et al. (2013). Social networks, the work and work force of chronic illness self-management: a survey analysis of personal communities. *Plos One, 8*. DOI:10.1371/journal.pone.0059723

Vassilev, I., Rogers, A., Sanders, C., Kennedy, A., Blickem, C., Protheroe, J., et al. (2011). Social networks, social capital and chronic illness self-management: a realist review. *Chronic Illness, 7*, 60-86. DOI: 10.1177/1742395310383338

Wilson, P.M., Kendall, S., & Brooks, F. (2007) The Expert Patients Programme: a paradox of patient empowerment and medical dominance. *Health and Social Care in the Community 15(5)* 426-438. DOI 10.1111/j.1365-2524.2007.00701.x

Ziersch, A. M., & Baum, F. E. (2004). Involvement in civil society groups: Is it good for your health? *Journal of Epidemiology and Community Health, 58*, 493-500. DOI:10.1136/jech.2003.009084

Ziersch, A., Osborne, K., & Baum, F. (2011). Local community group participation: Who participates and what aspects of neighbourhood matter? *Urban Policy and Research, 29*, 381-399. DOI:10.1080/08111146.2011.623295

**Tables and figures added**

**Figure 1 Sampling and Recruitment**

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**Table 1 Typology of Organisations**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Group ID** |  **Type of Group** | **Health Relevance/Function** | **Activities** | **Funding** | **Number of Members** |
| VA09 | Community centre afternoon club | Not obviously health related | Social activity group for older people. Activities include armchair exercises, arts and craft, and bingo. | Council grants and membership | 8 |
| VA10 | Hobby group | Health support – support group or network; counselling or mental health organisation; drug or alcohol service | Craft activities including knitting, tapestry, cross stitch and sewing, | Public funding (NHS), council grants and membership fees | 12+ |
| VA07 | Health support group | Health support – support group or network; counselling or mental health organisation; drug or alcohol service | Club activities include social, exercise, craft, peer support and outings. | Membership fees and donations | 25-30 |
| VM40 | Health support group | Health support – support group or network; counselling or mental health organisation; drug or alcohol service | Offers information, advice, support and education, organised outings, respite breaks and appropriate social activities. | Charity donations and council grants | 450 |
| VM26 | Hobby group | Provide some health related activities (or signpost) including exercise or healthy eating, but not main purpose of the organisation | Organised walks and social activities. | Membership fees | 300 |
| VM32 | NHS lifestyle service | NHS Service and/or deliver health projects and programme  | Health information, speakers and presentations, and social meetings. | Public funding (NHS) | 835 |
| VM33 | Befriending organisation | Health support – support group or network; counselling or mental health organisation; drug or alcohol service | Befriending, escorted shopping, sit in service for carers and social events. | Public funding and council grants | 70+ |

**Table 2 Participant Demographics**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Gender** | **Age Range** | **Who do they live with?** | **Household Income Range** | **Current Occupation** | **VCO Attendance** | **Long-term condition**  |
| Male 10 | 58 - 87 | Live alone 7  | £15,600-£20,799 to £52,000 or more per year | Retired 17  | Community centre afternoon club 2 | Diabetes 4 |
| Female 10 |  | Spouse/partner 12 |  | Full timeemployment 2  | Hobby group(s) 7 | CHD 12 |
|  |  | Spouse/partner withchildren over 18 1  |  | Carer 1  | Health support group(s) 4 | CKD and diabetes 1 |
|  |  |  |  |  | NHS lifestyle Service 6  | Diabetes and CHD 2 |
|  |  |  |  |  | Befriending organisation 1 | CHD and CKD 1  |
| Total  |  |  |  |  |  | 20 |
|  |

1. Mark Jeffries and Amy Mathieson are to be known as joint first authors [↑](#footnote-ref-1)
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