

Managing Your Health Together

**Voluntary Organisations, Community Groups and
Local Networks of Support**



Managing Your Health Together: Voluntary Organisations, Community Groups and Local Networks of Support

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Introduction

Who we are

We are members of the patient research theme within the Greater Manchester Collaboration for Leadership in Applied Health Research and Care (GM CLAHRC) which brings leading clinical experts together with world class researchers in the University of Manchester whose “know-how” is linked with that of frontline healthcare providers and commissioners. The aim of our work in the patient theme is to develop and implement innovations in care for people with long term vascular conditions (diabetes, chronic kidney disease, heart disease) that promote patient self-management, improve quality of care, and make more efficient use of NHS resources.

The aim of the **VOCALS** (Voluntary Organisations Community Groups And Local Networks of Support) study was to explore the role of voluntary and community organizations in supporting individuals to manage long term vascular conditions.

For many people the self-management of their long term condition is something they do outside of formal health services. Previously researchers have looked at how individuals and families might support this. There has been little focus on the role of other important resources in people’s networks. The CLARHC patient theme has therefore studied the support voluntary and community groups can offer people in helping them manage their chronic condition. For further information:

<http://www.implementationscience.com/content/6/1/56>.

This study also explored the formal and informal links between different voluntary and community groups and health services across Greater Manchester.

What we did

We conducted telephone interviews with 98 different community groups and voluntary organisations from four different areas of Greater Manchester. From this we sampled 33 groups to conduct face-to face interviews with organisation leaders. In addition, we observed group sessions with some of these organisations. Twenty interviews with members of different groups were also undertaken.

What will happen now?

The findings of the research were presented at academic conferences including Health Services Network Symposium in June, 2013, The British Sociological Association Medical Sociology and the Voluntary Sector and Volunteering Research Conferences in September 2013. The findings are also being written up for academic journals.

What this booklet is about

This booklet summarises some of the findings of our research and is for you to show some of the things voluntary and community organisations can do to help people with long term conditions.

What We've Found Groups Can Do

Information and Advice

We found that groups are places where people can get information about their condition and members can give each other advice. This could be solving practical problems, as discussed below:

"We have many conversations about walking sticks and there's actually a little gadget that you can put on the walking stick so that you can hang it on the table, and, erm...new people that join the group never know and there's walking sticks on the floor. And it's amazing, someone will say "what you need is, if you go on the market you can get one of these"..." [Paula, Manager]

Sharing these experiences helped people to understand and manage their own condition:

"Cos I, I, I would ne...I would need to know...you know, 'cos a...I think, I think until, until you know how somebody else is dealing with it, you know, how they go about it, er...that's the only wa...I think that's the only way you fi...you find out, 'cos, um, doctors, specialists, consultants can tell you all these wonderful things but it, it's how Joe Bloggs in the street deals with it...I think gives you more information, you know..." [Stanley, Member]

People at groups gave support to each other by making suggestions based on their own experience. Members of the group passed on hints and tips that have helped them with the day-to-day living with their condition:



“How do I think...? They get...er, everybody gives each other tips. They might only be small things...like, er, we had...used to have, um, a man called Mark, and when it were cold, he said one day, he can't put gloves on. And so one of them said, you wear mittens.” [Hazel, Volunteer]

As well as information, advice and support, groups can offer skills training to assist people in dealing with their condition. This may be healthy eating or diet related:

“Well is it...I look at this way, we've got...she's come out with portion things, she's come out with the, er, food diaries and...and all the rest of it, er, healthy heart and, and what else have you an...and spreads and, and fats and all, all, all the great things what, what you would probably get at Slimming World, but I said to everyone, I said [the] Council and NHS are running this and it's free...and they're telling you the same things that Slimming World would tell you.” [Stanley, Member]

“It’s a really friendly group”

There was companionship and camaraderie at groups; people socialised and were relaxed with each other. This encouraged people to get involved in the group activities and do things they previously thought would not be possible:

“...we’re going to do a sports day”, and there was a shout of “you are joking, have you seen my leg”. “This arm doesn’t work, how the hell can we do a sports day”, and I said “no we can, we’re gonna do this”, and we went outside and, erm...I’d made sure all the activities were sat down...so that everybody had an equal footing [...] we do welly wanging, we do tin can alley, we do erm...skittles, we do anything that people can do, we even do splat the rat. But the finale is always the egg and spoon race, and it’s amazing to see, everybody wants to do the egg and spoon race and the welly wanging on the field. And everybody just takes part, and it doesn’t matter...you know, it really does not matter and they just have so much fun. But that’s because they’re comfortable with each other and that’s the thing”. [Paula, Manager]

Companionship within the groups may extend to trips out, social events and other activities:

“I: What do you mean by the social side?”

Well the friendliness and you don’t feel isolated or...plus we go on a trip and we have a Christmas meal and so it’s really good. Like I say you meet other people and you get to know about other things. There’s one lady she makes, erm, quilts. And there’s a quilting exhibition and we’ve bought, we’ve been asked do we want to go to that so that’ll be another afternoon. So it, it spirals really into other things.” [Florence, member]

By being a member of a group, people have a sense of belonging and sharing together. There often isn't any 'pressure' placed on the member and instead people are encouraged to participate as little or as often as they like:

*"Nobody pushes them, nobody mithers them. If they don't come this week, they'll come again next week and we will say oh we missed you last week or where were you last week, I want a note from your mother. Thi...you know, a bit of fun. And there's no pressure put on any of them...so no matter what their health problem is as long as they're able to come out...this is an ideal place for them."
[George, Volunteer]*



Groups were welcoming and accommodating, working to include people:

“And he wants to come...when Hillary were trying to get the transport, she's...we've had to think about the people that are in wheelchairs as well, you know.....fitting in the bus, all being part of our group.” [Hazel, Volunteer]

Because of this and the companionship within the groups, people felt comfortable to discuss their health problems:

“I think it alleviates it a lot, I think it just give you the, you know, 'cos hearing this question and putting things back in perspective I think is important as well. You know that...and I think, you know, sharing experiences with other people is very, very helpful indeed. It helps you to put your own issues forward and if you need to go and see your doctor or whatever you can articulate a little bit better...” [Paul, Service User]

Regularly going to a group offered opportunities for new social contacts and people could make new friends:

“Whereas we are totally different [...] it's making a friendship. Although we do have barriers ...and we do have policies and procedure...and, um, boundaries...it's still a friendship. So they will expect that person to be friendly with them.” [Susan, Manager]

People enjoy socialising in the group and often ‘have a laugh’, as Agnes describes below:

“I have a laugh with them, because there's the...the, the group is lovely [...] the banter is delightful...and we used to get there 20 minutes early to sit around on chairs just bantering with each other...and I love that. So I was going for the banter ...” [Agnes, Member]

Getting Support and Gaining Confidence

We found that going to a group empowered people by building their confidence and self- esteem:

“Well, I absolutely love it. And it's given me, um, something in me life. You know, it's like I've been reborn again, if you like.” [Hazel, Volunteer]

This included encouraging people to manage their condition. Going to a group, as Paul discusses below, gave him the confidence to take responsibility for his health:

“But I think again this is the thing it does is it encourages you but, of course, I come from an era when if you were ill you went to the doctor and the doctor sorted you out type of thing. The lack of personal responsibility and it's still evident. You know, a lot of people, you know, they tell me at the diabetic centre ignore their advice and just carry on as before. Erm...you know, whereas this sort of a grouping where you get the continuous thing encourages good behaviour

I: Why does this network then encourage that do you think?

Oh I think obviously your friends...well they wouldn't be close friends if they weren't supporting you in that and encouraging you they wouldn't help. Erm...the group, the entire group, the instructor, and the people there help as well.” [Paul, Service User]

Similarly, members offered emotional support to one another; cheering each other up and helping others to forget their problems:

“But it does help because if you’re just feeling a bit down or worried about anything you but then you forget all about it and...”

I: So how do you forget all about it?

Well it’s the stitching and the chatting to other people and you usually realise there’s plenty worse than yourself so not as bad as you thought.” [Florence, Member]



Support was described as a 'big comfort blanket' by one of the group leaders:

"And they just seem to have, it's like one big hug comfort blanket I find. And the members themselves are so, so supportive of each other. And it's fantastic to watch how it works within the group setting really, you know, you...as I say, yes we're the ones that make it happen but as you take a step back it's the members themselves that support one another." [Paula, Manager]

Groups also gave practical support; such as here where a member was helped to renew her bus pass:

"We send information in, if there's anything...any services they need signposting to, we can do that. So if they're a little bit worried when they come into the drop-in...we'd one lady, hadn't we, and she said, um, oh, my bus pass needs renewing but I can't sort it out, I don't like using the phone. And she'd been worrying and worrying about it. And she came into the drop-in and we did it..." [Susan, Manager]

Emotional and practical support made people feel they were not alone and helped them to maintain their independence:

"My members discuss it as falling through the black hole when you come out of hospital, you seem to get so much support when you're in there but then when you come home it's just what now, you know, and people feel very isolated and left to their own devices" [Paula, Manager]

Being Active

People who attend groups get involved in community sports, leisure activities and exercise to keep fit and active:

"...we have people that have been with us from the very start, erm, we have a guy who does [the run] who, who's 80-something, and he runs with a crash helmet on, he runs there and he runs back, Nigel, he's always last [...] it's that sort of community feel for a lot of the stuff that we do..." [Max, Paid Employee]

Some of these leisure activities within the community were follow-up programmes offered to people who had received treatment from the NHS. These encouraged people to keep exercising and gave them the opportunity to do so:

"Well I think the benefit in life from the earlier sessions I think, you know, I recognised and, therefore, I wanted to continue with that to keep myself generally fit. And its part of a routine, I mean I think again it's the discipline of going to a class." [Paul, Service User]

Exercise offered by groups could be beneficial for the members' health and well being, by integrating other hobbies or members' interests in other activities:

"So what we try and do is create, um...do creative things that have got some benefits, um, in terms of health and wellbeing. So whether it be meditation, whether it be a hula hoop class...whether it be the fact that we got everybody in the garden digging, or we're going up to the park where we've got another space up there. So it's horticulture and they're being trained in that, but it's also about exercise, being out in the environment..."[Jayne, CEO]

For example fishing:

"I think by keeping more active...because obviously people take part in the activities that we do, erm...as I say, the fishing that we've set up now...and the gentlemen, there's two in wheelchairs and I met them both yesterday and they said "I never thought we'd go fishing again"..." [Paula, Manager]

And cycling:

"...he came up with the diabetes and losing weight and all the rest of it...it's sort of like a wake up call, and because I've gone down this road, like my therapy started in August, when I've gone down this road of exercises, armchair exercises and so on and so forth, but only be...I can do...I can do things...that I thought I couldn't do. And with like the, the specially adapted bikes, I can do something I thought I'd never be able to do ever again. And it's something I'd not done since 40 years..."
[Stanley, Member]



Getting Out and About

Groups make sure people don't miss out on activities and members have somewhere to go:

"One lady comes, em, two bus rides, er, and she's the one who's good at crochetry; but she comes for the company, so when we don't have a meeting she misses it. So what we do in the summer break [...] one of the members will volunteer and say, well, come to my house. So tomorrow we're going, we're going to a lady's house in town, er, because she's going to host the afternoon, you know, so to keep us together during the summer" [Daphne, Volunteer]

Groups made the effort to stay in contact with members who can no longer participate in the group's main activity. This continued contact maintained friendships and reduced isolation:

"...you can be very cut off in a [walking group] 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. And, um, a lot of us have found it very beneficial to keep in touch...and keep up with the gossip." [Agnes, Member]

We found that groups offered people the opportunity to have a break from their health problems:

"But, as I say, with the elderly they've got the, the problems like heart problems, um...diabetes, kidney problems, all kinds of things like that. Um, but because they're the type of people that use the community centre...although some of them go on a bit, but they put that to the back of their mind. They try and lead a normal life...because they know there's somewhere like this that they can come." [George, Volunteer]



Going to a group also gave carers a break and allowed people to get out and about with their friends from the group:

"[...] one, two, three, four...seven of the men from the group, we went to see Skyfall [...] because there was seven of us together...we didn't n...need a carer [...] Hazel and John from the stroke...all right, they met us there and they went off to do something else, but when we were inside the cinema there was only us seven [...] we knew that if anything happened to any of us, we were taken ill or whatever...there was enough of us there to get some help...if, if need be. So trust was put in ..."
[Stanley, Member]

Doing Something Different

People going to community groups might be taking up a new hobby or interest. It gives people the opportunity to get involved in the community or learn a new skill:

“Yes, because when I retired about ten years ago I decided I’d learn a new skill. And I’d always wanted to do some kneelers for church, which involves cross-stitching; but that is like a kit and it’s really quite straightforward to do.” [Florence, Member]

Members could feel they were doing something for the wider community:

“I...and because I was interested in stitching, as I’d already said I’d already done lots of things for church, I thought, ‘Right, I’ll be part of that’, and whatever stitching we do will be a legacy in the community because the finished piece is to go in to the health centre, the new health centre, permanently; so when I’m dead, in 50 years time people will...there’ll still be a legacy of stitching and memories there.” [Daphne, Volunteer]

Participating in many new and different activities was seen as good for health and well being:

“I mean they’re very lucky, and they would benefit from something like [this] group. They meet people, they do these exercises and have a laugh, they do crafts, er, we do bowling with them, we do skittles with them...Snakes and ladders with them. We do all sorts of daft things with them. And to be honest...They’ve drawn the line, they’ve drawn the line at bungee jumping.” [George, Volunteer]

Different activities could be seen as an alternative to mainstream services. Here the group leader felt that taking part could develop people in positive ways:

“I'm interested in people coming here to help them get well through using creative arts and horticulture as a way of, you know, reaching their full potential; er, raising their aspirations; helping them to be more confident; and giving them pathways into other things that they never thought they'd get.” [Jayne, CEO]

Connecting to Other Groups

We found the groups have formed good connections with a variety of services in the local community. Because of their knowledge of what is available in the area, groups were able to signpost people onto different organisations:

“Through the peer support we set up on the website, it's called the guidebook, and we spent lots and lots of time a few years ago speaking to our members to find out what support did they feel they needed [...] And then we had a look at what services were available across the borough and now obviously we could link those people together so that they can get that support. Erm...and that's an important role that we play as well.” [Paula, Manager]

Groups had established links in order to receive referrals from other providers including NHS services:

“Um, I'm just trying to think of people, the organisations that we will refer people to that, um...I mean, OT, you know, the NHS occupational therapists...er, for, you know, referrals for people discussing and helping us understand a person, because they've spent some time with them. So, um...you know, sort of professional relationship with discussing things if somebody's referring or has referred somebody in the past.” [Susan, Manager]

Conclusion

Voluntary and Community groups have the resources to help people with chronic health conditions. We found that:

- ❖ People could get Information and advice around their long-term condition management at the group. This might include access to written information, tailored advice given face to face or in peer support sessions.
- ❖ With many groups there is a sense of belonging and sharing together. People made new friends and increased their social contacts. Groups were often welcoming and accommodating.
- ❖ The groups gave people confidence, built their esteem and helped them maintain their independence. Many of the groups also offered practical support.
- ❖ The groups were somewhere to go to socialise and do something different. The groups may also provide time away from concerns around health. Members benefited from knowing there was support available if they needed it.
- ❖ Members engaged in new hobbies or interests. These leisure activities might involve health-based exercise such as walking, dance or rehabilitation exercises at a local leisure centre. This could be an alternative, or complimentary, to mainstream health care.

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Active Living Wigan

Art to Art

Asian Elders Resource Centre

Bolton Care and Repair

Bolton CHA Rambling Club

Bolton CVS

Bolton Little Theatre

Bolton U3A

Bolton West Stroke Group

Bramhall U3A

Brightmet UCAN

Brinnington Arts and Music

Brinnington Community Centre

Daisy Chain Stitchers

Dean UCAN

Get Active Bolton

Halliwell Befriending Service

Halliwell Local History Society

Horwich Resource Centre

Leigh and District Camera Club

Mud to Muscle

Parkinson's UK Bolton Branch

Quintessential Quilters

Start in Salford

Stockport Afternoon Flower Club

Stockport Arts on Prescription

Think Ahead

Time2Communities

Tonge Moor UCAN

Walmsley Church AODS

Westhoughton Visiting Service

Wigan Piertown Chorus

Wigan Rambling and Climbing Club

Useful Websites

<http://clahrc-gm.nihr.ac.uk/>

<http://www.population-health.manchester.ac.uk/primarycare>

<http://plansforyourhealth.org/>