

Connecting to local networks of support: a qualitative study exploring the role of voluntary and community groups in long term condition management

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Aims

To explore the existing and potential role and function of voluntary organisations (VOs) to support long term condition management

How do people manage long term conditions?

- Increasing prevalence of people with long term conditions of which 80% are expected to self-manage
- Self-management has primarily focused on the individual and neglected the wider social context (Kendall & Rogers, 2007)

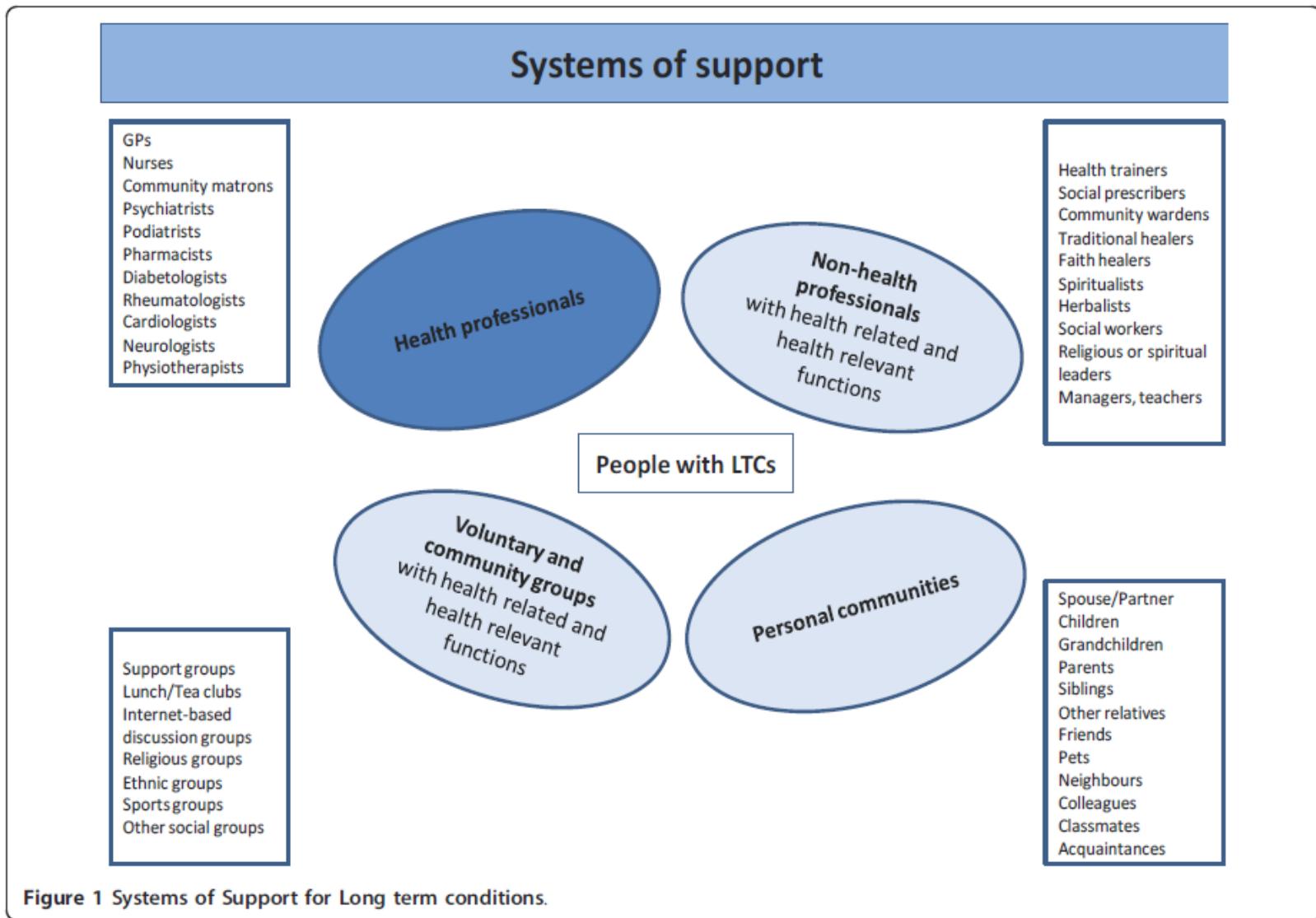


Figure 1 Systems of Support for Long term conditions.

Rogers et al (2011)

What do voluntary groups do to support LTCM?

- Approximately £3.39 billion is spent annually on funding health related activities provided by VOs (Clark et al, 2010)
- 35,000 VOs deliver health and/or social care services in England and 14% of only deliver health care (Dickinson & Miller, 2011)
- In chronic illness management, VOs have a history of providing training to patients as peer support and promotion of health lifestyle behaviours (Kennedy et al, 2005; MacDonald et al, 2009)

Methods

- 33 semi-structured interviews with organisers of VOs in North West of England
- VOs ranged from directly to not directly health relevant (e.g. fitness programmes, art groups)
- Interviews explored a range of topics including sustainability, links to health services, local context and the organisations social networks
- Analysis: thematic as well as narrative

Results

- Roles in supporting long term condition management (LTCM)
 - Explicit
 - Implicit
- Organisational features which influenced this role

Explicit role in LTCM: Pathway of care

*...the main bulk of our work is around creative activities and horticulture... I think that if we find when we're talking to people who have got significant problems, that we'll link them in with another team. ...so if they've got diabetes or, er, heart problems, or some of them have come from the brain and spinal injury... we're providing, er, a **complementary piece of the jigsaw really.***
ID VM38 (organiser of an arts and wellbeing centre)

Translation of health messages

*for people to take ownership of health... it's got to be done on a very gradual process, where they feel that they're being rewarded for...and having the **knowledge of your community** ...not to contradict, but the PCT, the public health, have set health messages, and I personally feel that they're not appropriate here, and I work **them same health messages differently***

ID VM31 (organiser of a community development centre)

Implicit role: Space to be 'normal'

*I get a lot of people as well, who have a lot of physical health issues as well, erm, who come, so they're managing quite painful physical health...But it's been a chance for them to come out and do something **normal**...You know, just mix with other people*

ID VM39 (organiser of a hobby activity)

*they wouldn't see us as a health activity...I think people's view is that the NHS is dealing with things on a medical level...but clearly the **boundaries between social aspects of life and medical aspects there's a great, big, grey area in the middle...***

ID VA08 (organiser of an education group)

Organisational Features

Organisation features	Characteristics		
Funding Source	Member payments		External grants
Role of location	Community need		Policy driven
Organisation users	Members	Participants	“Clients”
Organisers	Volunteers	Mix of paid staff and volunteers	Paid staff

Type of group activity	Ideology		Funding Source (15 groups had more than one funding source)				
	Member focused (n=)	Community focused (n=)	Charity (n=)	Grants (n=)	Public Funding (n=)	Contribution from group participant (n=)	Other (n=)
Hobby activity (n=14)	11	3	0	3	2	11	4
Community centre (n=4)	1	3	1	2	2	2	1
Providing community / voluntary organisation/ personal support (n=12)	0	12	2	3	10	4	2
Other (n=3)	0	3	0	2	2	0	1

Connections to health services

Type of group activity	Front line services (e.g. hospitals, GP surgeries, NHS programmes) (n=)	PCT/ CCG/ Department of Health (n=)	No connections to health services (n=)
Hobby activity (n=14)	1	2	12
Community centre (n=4)	0	2	2
Providing community/ voluntary organisation/ personal support (n=12)	9	9	0
Other (n=3)	3	2	0

Organisational influences: *Ideology of the group and volunteers*

I think it's just being part of, um, a supportive group of people really.... everybody's there for everybody else...

ID VM30 (organiser of a hobby group)

... we have a chat about, eh, how long have you had your diabetes for, do you go and visit your doctor regularly... if we have that rapport with that person whose talking to us, we can help build that capacity, pass on, you know, use your building relationships to signpost to the appropriate services, and be there for them really.

ID VM31 (organiser of a neighbourhood development organisation)

Organisational influences: *constraints of funding*

*[group] funded through what was – and still is – [location] Primary Care Trust... basically its aim is to encourage the uptake of physical activity, that's its, its one stated aim really; but within that **we do work around**, em, we have a cycling development worker who does things like, em, er, health rides three or four times a week.. We only work with adults, em, originally the programme was funded by, er, [funding source] which specified the areas that we could work in and also the age group...*

ID VM32 (organiser of a physical activity group)

Organisational influences: *constraints of funding*

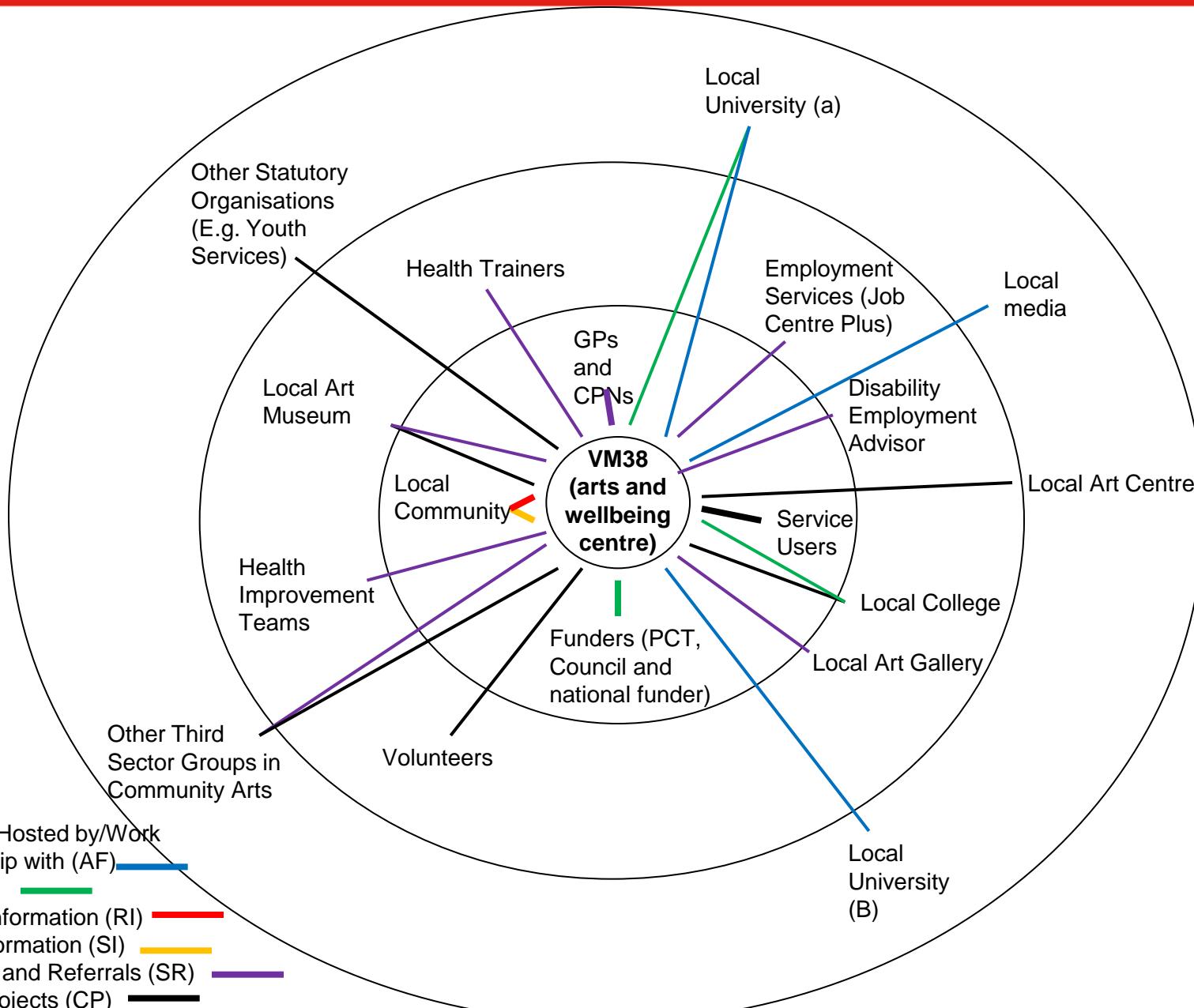
we have looked at doing pieces of work with particular target groups with long term conditions, but in order to do that, we've got to find some money to do it... now obviously, if we do things properly and we monitor it, we might be able to go back to the commissioners and say, this is what really works well and you need to invest in it. But what we tend to find is, we have to find the money to do a project first and then go to somebody and say, this has worked. So it is hard really.

ID VM38 (organiser of an arts and wellbeing centre)

Organisational influences: *liberations of funding*

*..the [group] are about 90 per cent funded by the Primary Care Trust...we have a number of different physical activity and weight management contracts with the Primary Care Trust...Which is working in partnership with local health professionals, so doctors, physios, specialist nurses, so we have close links with the hospital cardiac rehab service...they refer patients to us which we then **signpost into lots of different types of physical activity***

ID VM22 (organiser of a physical activity team that works with different groups to increase physical activity



Organisational influences: *pathways of sustainability*

...we found round here there is such a lot of well-being issues...[wellbeing group] have a staggered system where they can refer on if, you know, they need something else... alcohol and drug support group...So they come in and meet upstairs over coffee, and do some work... the PCSOs in, they pop in all the time...They're running a surgery every Thursday now for an hour... the councils are starting them in a surgery...so we're trying to get involvement with everybody

ID VM44 (organiser of a neighbourhood development organisation)

Conclusions

- Group organisers viewed their role as either directly or indirectly health related
- VOs are a source support for people with LTCM by addressing a range of complex issues
- Complimentary to existing self-management programmes by addressing broader health and social issues
- Ability of VOs to be responsive to local communities may be constrained by funder requirements of organisational structure and differing ideological perspectives

Future work

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What is PLANS?

PLANS is an online way to help you assess your health and social needs. Based on your responses, the internet programme will suggest local community services and activities that are likely to be of interest.

Keeping active, being involved in social activities and being able to find support (such as information about your health or help with everyday things) have been shown to have many health benefits. These include reduced anxiety; improved quality of life; and improved feelings about general health.

As well as doing things for yourself, you may be interested in

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Everyone is different and we need different things to help us manage our health and enjoy life. To help you find activities and support in your area we have developed the PLANS questionnaire which aims to help you think about what you can do to manage your health.

As well as doing things for yourself, you can also plan ways to use support from your local community. PLANS can help you find local healthy activities such as exercise or diet groups. PLANS can also help you find activities that you might enjoy such as social or hobby groups.



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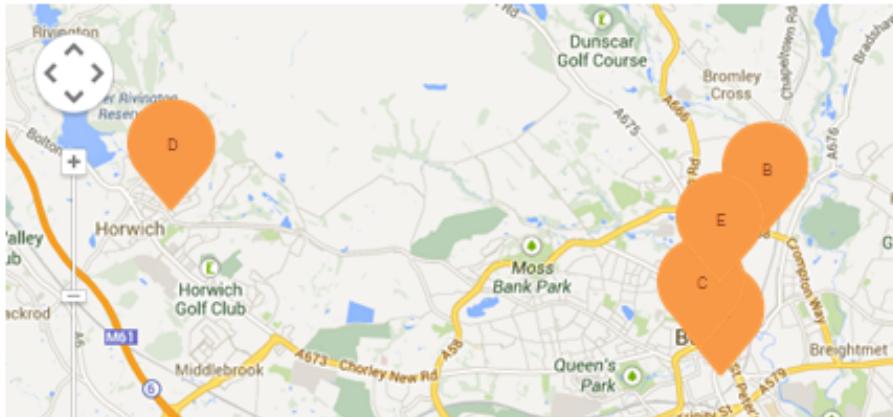
Show Results Within: 1 Mile 2 Miles 5 Miles 10 Miles

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