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

<table>
<thead>
<tr>
<th>Organisation features</th>
<th>Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Funding Source</td>
<td>Member payments</td>
</tr>
<tr>
<td></td>
<td>External grants</td>
</tr>
<tr>
<td>Role of location</td>
<td>Community need</td>
</tr>
<tr>
<td></td>
<td>Policy driven</td>
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<tr>
<td>Organisation users</td>
<td>Members</td>
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<tr>
<td></td>
<td>Participants</td>
</tr>
<tr>
<td></td>
<td>“Clients”</td>
</tr>
<tr>
<td>Organisers</td>
<td>Volunteers</td>
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<tr>
<td></td>
<td>Mix of paid staff and volunteers</td>
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<td></td>
<td>Paid staff</td>
</tr>
<tr>
<td>Ideology</td>
<td>Funding Source (15 groups had more than one funding source)</td>
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<td>-------------------------------------------------------------</td>
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<tr>
<td></td>
<td>Member focused (n=)</td>
</tr>
<tr>
<td>Hobby activity (n=14)</td>
<td>11</td>
</tr>
<tr>
<td>Community centre (n=4)</td>
<td>1</td>
</tr>
<tr>
<td>Providing community / voluntary organisation/ personal support (n=12)</td>
<td>0</td>
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<tr>
<td>Other (n=3)</td>
<td>0</td>
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</tbody>
</table>
## Connections to health services

<table>
<thead>
<tr>
<th>Type of group activity</th>
<th>Front line services (e.g. hospitals, GP surgeries, NHS programmes) (n=)</th>
<th>PCT/ CCG/ Department of Health (n=)</th>
<th>No connections to health services (n=)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hobby activity (n=14)</td>
<td>1</td>
<td>2</td>
<td>12</td>
</tr>
<tr>
<td>Community centre (n=4)</td>
<td>0</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Providing community/ voluntary organisation/ personal support (n=12)</td>
<td>9</td>
<td>9</td>
<td>0</td>
</tr>
<tr>
<td>Other (n=3)</td>
<td>3</td>
<td>2</td>
<td>0</td>
</tr>
</tbody>
</table>
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
VM38 (arts and wellbeing centre)

Key
Affiliated to/Hosted by/Work in Partnership with (AF)
Funding (F)
Receiving Information (RI)
Sending Information (SI)
Signposting and Referrals (SR)
Common Projects (CP)

Other Statutory Organisations (E.g. Youth Services)
Local Art Museum
Local Community
Health Improvement Teams
GPs and CPNs
Volunteers
Health Trainers
Local Art Centre
Local College
Local University (a)
Local Art Gallery
Local media

Funders (PCT, Council and national funder)

Service Users
Disability Employment Advisor
Employment Services (Job Centre Plus)

Other Third Sector Groups in Community Arts
Local Art Centre
Other Statutory Organisations (E.g. Youth Services)

Health Trainers
Local Community
GPs and CPNs
Volunteers
Health Improvement Teams

Key
Affiliated to/Hosted by/Work in Partnership with (AF)
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Common Projects (CP)
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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