Shared Decision Making & Self Care

www.selfhelp.org.uk
Twitter: @selfhelpteam
0115 911 1662
"Mobilising the contribution, talent, expertise of the patient, parent, carer"

1. The link between patients as individual decision makers and the wealth of community support available to inform choice.
2. The intricacies of engaging peer networks alongside professionals as a proven way of transferring knowledge and supporting change (in both directions!).
3. The key principles and outcomes of mutual aid and self help and how they relate to shared decision making and co-production.
4. The common concerns of professionals about ‘experts by experience’ groups and the keys to a good relationship to leverage social capital.
5. The realities of asset based community development, collective learning and how information is best packaged.
6. Feedback from patients in self help groups on the “3 questions” campaign.
Provides services to support people with long term conditions, their carers and the professionals who work with them to develop self help support groups

- Established in 1982, Registered charity since 1997
- A Department of Health sponsored innovation partner
- Working across East Midlands region to improve user involvement
- Nottingham Social Enterprise of the Year 2011
- ESTEEM (Effective Support for Self Help/Mutual Aid Groups) research partner
“The greatest untapped resource is patients themselves

IF they are supported by health and social care professionals to have the confidence to take control and manage their conditions better”
What patients want... (Picker, 1m patient study)

- Fast access to health advice
- Effective treatment delivered by staff you can trust
- Involvement in decisions & respect for patients’ preferences
- Clear, comprehensible information & support for self-care
- Physical comfort and clean, safe environment
- Emotional support and alleviation of anxiety
- Involvement of family and friends and support for carers
- Continuity of care and smooth transitions.
The five key areas of self care support include:

- **Information** – about the condition, in a way that people want, when they want it.
- Services to support **healthy lifestyle** choice e.g. smoking cessation.
- General or condition-specific **training courses** to help people feel more in control.
- Access to & information about **support networks/self help groups**.
- **Tools and equipment** to help better manage their condition better & stay independent.
A systematic approach to self care support

IT: clinical record of care planning

Send test results beforehand

'Prepared' for consultation

Information / Structured education

Emotional and psychological support

Engaged, informed patient

Organisational processes

Collaborative care planning consultation

HCP committed to partnership working

Consultation skills / attitudes

Integrated, multi-disciplinary team and expertise

Senior buy in and local champions to support and role model

Commissioning – the foundation
The reality: The individual's perspective

......making better use of NHS / social care contact time

Like professionals, patients are continually refining their opinions on illness & treatment

Hours with NHS professional
= 3 in a year

Self care / management
= 8757 in a year
Quality Improvement Productivity & Prevention (QIIPP) Right Care Shared Decision Making Programme

Aim: to embed the practice of shared decision making among patients and those who support them, and among health professionals and their educators.
"The key components of SDM identified by NHS staff (PART 1):

• patients and service users who have:
o the information and literacy skills they need to understand the options available to them, and the implications of their choices;
o the knowledge and confidence they need to participate in the decision-making process as much as they want to;
o the skills and support they need to implement decisions successfully where these require (for example) adherence to treatment plans and/or lifestyle changes;

Supporting Shared Decision-Making: A PATHFINDER PROJECT FOR NHS NORTH WEST, (Picker Institute Europe, 2011)
“Information is helpful, particularly if it is personalised but information alone is not enough. It needs to be supplemented by decision support, personalised care planning and self-management education from well-trained health professionals, as well as social support from family, friends and peers. There is evidence that this can improve people’s understanding and level of participation, as well as their coping skills and confidence to self-manage, leading to better health outcomes.”
Ever felt alone with a problem?

Have you ever noticed that when you have a problem, how it helps to talk with someone who has had a similar problem?
Self Care Support by health condition group

- Arthritis and other musculoskeletal
- Asthma, COPD and other respiratory
- Cancer
- CHD
- Dermatological
- Diabetes
- Epilepsy
- Mixed
- HIV/AIDS
- Incontinence
- MS
- Obesity
- Pain
- Parkinson's
- Sickle cell disease
- Spinal cord injury
- Stroke

- Minor Ailments
- Long term conditions
- Public Health and Lifestyle
  - Physical activity
  - Addiction
  - Smoking

- Woman and Child

- Mental Health
  - Alzheimer's
  - Behavioural disorder
  - Bipolar disorder
  - Chronic fatigue syndrome
  - Depression
  - Eating disorder
  - Insomnia
  - Mixed
  - Mental Health
  - Schizophrenia
  - Social phobia

DH Research Evidence on the Effectiveness of Self Care, 2007
Who do patients listen to?

messages transmitted via peers are more credible

(A rapid review of the current state of knowledge regarding lay-led self-management of chronic illness DH Evidence review December 2005)

“Patients often lack relevant information and often feel disempowered by this. The power imbalance between clinician and patient can make patients reluctant to explore issues of concern to them. But informal sources of information are trusted more and encourage self caring behaviours with greater consistency.”
“Individuals who are socially isolated are between two and five times more likely than those who have strong social ties to die prematurely. Social networks have a larger impact on the risk of mortality than on the risk of developing disease, that is, it is not so much that social networks stop you from getting ill, but that they help you to recover when you do get ill.”

What is a Self-Help group?

informal networks of individuals who share a common experience or issue. The primary focus of self-help is sharing: mutual emotional support, practical support and information exchange. The group is primarily run by and for its members who have a sense of ownership.

Canadian Self-Help Clearing House
There is no conclusive definition of self-help groups

There is no conclusive definition of self-help groups. They emerge and develop in response to their social policy context (Borkman & Munn-Giddings, 2008). In the UK there has been little research on self-help groups compared with the US. However, the common characteristics identified by Self Help Nottingham are widely accepted and used by researchers. These include:
• members share a similar condition or life situation
• members come together to exchange information and strategies to address their problem
• sharing experiences enables the group to provide a unique quality of mutual support
• groups are run for and by their members

## More Dimensions (Adapted from Borkman)

<table>
<thead>
<tr>
<th></th>
<th>Self-Help / Mutual Aid</th>
<th>Professionally-led</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Knowledge emphasised</strong></td>
<td>personal experience</td>
<td>training/education</td>
</tr>
<tr>
<td><strong>Type of Leader(s)</strong></td>
<td>“all of us”</td>
<td>&quot;outsider&quot;</td>
</tr>
<tr>
<td><strong>Focus of meetings</strong></td>
<td>mutual support</td>
<td>guidance</td>
</tr>
<tr>
<td><strong>Structure</strong></td>
<td>informal</td>
<td>formal</td>
</tr>
<tr>
<td><strong>Decision Making</strong></td>
<td>everyone</td>
<td>led by facilitator</td>
</tr>
<tr>
<td><strong>Resources Used</strong></td>
<td>volunteer and &quot;in-kind&quot;</td>
<td>paid staff, fees or funding</td>
</tr>
<tr>
<td><strong>Duration</strong></td>
<td>ongoing</td>
<td>time-limited</td>
</tr>
<tr>
<td><strong>Evaluation/ Monitoring</strong></td>
<td>decided by members</td>
<td>often required by funder</td>
</tr>
<tr>
<td><strong>Development</strong></td>
<td>Grassroots</td>
<td>Top-down</td>
</tr>
<tr>
<td><strong>Attendee Role</strong></td>
<td>Voluntary Participants</td>
<td>Mandatory Recipients</td>
</tr>
</tbody>
</table>
Proven benefit

• Reduce use of health services & increase use of appropriate services
• Improve treatment adherence
• Increase positive health behaviours
• Cost effective
• Sustainable outcomes

Self help groups provide a highly cost effective solution in the drive to increase and improve self care whilst reducing costs and improving outcomes; research suggests that peer led support groups have a cost benefit ratio of 34:1

DH 2007
2.3 “shared decision-making” to become the norm.

International evidence shows that involving patients in their care and treatment improves their health outcomes, boosts their satisfaction with services received, and increases not just their knowledge and understanding of their health status but also their adherence to a chosen treatment. It can also bring significant reductions in cost, as highlighted in the Wanless Report, and in evidence from various programmes to improve the management of long-term conditions.
The evidence base....

- Reduced outpatient appointments
  Humphreys and Moos (2001)

- Reduction in re-hospitalisation

- Better treatment adherence

- Improvement in mental health indices
  Liberman & Bliwise (1985)

- 82% reported coping better
  Kurtz (1988)

- Patients lived longer

- Peer led groups 50% cheaper than professionally led
  Peterson et al (1985)

(Research Evidence on the effectiveness of Self Care Support, DH, 2007)
Proven benefit

- Reduce use of health services & increase use of appropriate services
- Improve treatment adherence
- Increase positive health behaviours
- Cost effective
- Sustainable outcomes

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Extending your reach to the underserved

“There is much emphasis – across health and social care services - on the need to reach out to ‘hard to reach groups’, and peer support has been found to be an effective method of doing this”

“User Led Organisations add value in providing services because they are driven and directed by the very people they help. They help statutory bodies to improve their understanding of the impact of their services on local communities, to engage with different groups of service users .... to reach population groups that are seldom heard and hard to find. This may result in more effective commissioning of services that better meet the needs of local communities.”
What are the benefits for patients?

“Being able to point someone in the direction of a specific support group could make the difference between someone living independently with a condition, or just living with it.”
Likely Impacts on the Quality and Productivity of Services

“Self care works, produces excellent outcomes, improves clinicians' job satisfaction, reduces workload and saves money”

“Self-help groups are worth developing, are valued by participants and are able to deliver a range of benefits at modest cost. But to be successful and sustainable they must be founded on high quality provision - in their establishment, in their selection of venues, recruitment, training and supervision of facilitators, and in networking with other agencies.”

(Promoting Optimal Self Care – Consultation techniques that improve quality of life for patients and clinicians, Dorset and Somerset SHA, 2006)

(Self-help support groups: a study of their role in recovery from depression, National Programme for Improving Mental Health and Well-Being, 2006)
<table>
<thead>
<tr>
<th>Finding</th>
<th>Area</th>
<th>Authors</th>
<th>Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Validation of their approaches to problems increase their confidence and establish a sense of normalcy for themselves. Comparing one another to each other is considered to provide other peers with an incentive to change for the better either through upward comparison (looking up to someone as a creditable role model) or downward comparison (seeing an example of how they used to be and realising the progress they’ve made). Those helping each other feel greater interpersonal competence from changing other's lives for the better.</td>
<td>Peer Support Among Individuals with Severe Mental Illness</td>
<td>Davidson, Chinman, Kloos, Weingarten, Stayner, Kraemer</td>
<td>1999</td>
</tr>
<tr>
<td>Finding</td>
<td>Area</td>
<td>Authors</td>
<td>Year</td>
</tr>
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<tr>
<td>experienced significantly greater (1) increases in the size of their support network, (2) increases in their knowledge of community resources, (3) improvement in their interpersonal skills and ability to deal with the problems of caregiving, (4) <strong>improvement in their relationships with their care receivers</strong>, and (5) decreases in pressing psychological problems.</td>
<td>Carers for the elderly</td>
<td>Toseland, Rossiter and Labrecque</td>
<td>1989</td>
</tr>
<tr>
<td>Personal empowerment is a form of <strong>social capital</strong> derived from engagement in the social relations within the self-help group that allows members to obtain benefits such as increasing their life satisfaction.</td>
<td>Hong Kong self-help groups</td>
<td>Chung, Mok and Chung</td>
<td>2005</td>
</tr>
<tr>
<td>Finding</td>
<td>Area</td>
<td>Authors</td>
<td>Year</td>
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<tr>
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<tr>
<td>can lead to effective coping skills, improved self-esteem and personal growth, and <strong>collective mobilization</strong> for social change and service innovation.</td>
<td>General review</td>
<td>Hasenfeld and Gidron</td>
<td>1993</td>
</tr>
<tr>
<td>Members reported personal gains of empathy, emotional information, <strong>experiential knowledge</strong> and practical information, based on a core value of <strong>reciprocity</strong> through peer support</td>
<td>carers</td>
<td>Munn-Giddings and McVicar</td>
<td>2006</td>
</tr>
<tr>
<td>Learning as an empowerment process: consciousness-raising, acquisition of objective knowledge, learning from others' experiences and discovery of new perspectives in life and in oneself.</td>
<td>women recovering from breast cancer and participating in self-help groups</td>
<td>Stang and Mittelmark</td>
<td>2008</td>
</tr>
<tr>
<td>Major facilitator of activism-involvement in improving the medical system</td>
<td>parents of children with cancer</td>
<td>Chesney and Chesler</td>
<td>1993</td>
</tr>
</tbody>
</table>
Helping Factors within the Framework of Self Help

*Universality* the finding of similarity in self help groups. Discovering you are not alone with your problem and that there are other people who have gone through something similar.

*Information* imparted by:
- group members sharing experiential knowledge
- guest speakers and professionals
- literature/printed information

*Instilling Hope* and inspiration can develop when newcomers listen to members tell their stories of recovery. Newcomers identify with the “what we used to be like” portion of the story and can feel inspired by the way people have chosen to live their lives.

Why Self Help Groups Work: Hope?

When people attribute negative things in life to internal, stable and global factors (pessimism) they can get into a state where they feel powerless to change their self or situation.

A perceived absence of control over the outcome of a situation can lead to inaction even when the opportunity is restored for self help (Seligman, 1975).

Self Help groups empower members to overcome this debilitating ‘learned helplessness’ by allowing more choices in response (responsible and response-able)
Why Self Help Groups Work: Helper Theory?

Riessman (1965), attempting to explain the therapeutic effect for both people in a "helper" and "helpee" relationship within groups: In the process of helping another member, the helper gains an increased sense of self-efficacy making the relationship mutually beneficial.

Those helping each other feel greater interpersonal competence from changing other's lives for the better.
The helpers feel they have gained as much as they have given to others. The helpers receive "personalized learning" from working with helpers. The helpers' self-esteem improves with the social approval received from those they have helped, putting them at a more advantageous position to help others.
Stages of Group Development

STAGES OF GROUP DEVELOPMENT

FORMING
TRANSFORMING
STORMING
PERFORMING
NORMING
ADJOURNING
“The majority of groups in the sample closed before becoming ‘established’, that is, before having started to function properly as a group by, for example, holding regular meetings. This seemingly high figure is in line with USA studies that similarly suggest a high turnover rate.”

Table 3 Reasons for groups’ closure at different stages of maturity

<table>
<thead>
<tr>
<th>Age of group at closure (total number of groups)</th>
<th>1–3 years (74)</th>
<th>4–6 years (43)</th>
<th>7–9 years (26)</th>
<th>10 or more years (49)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Key member withdrawal</td>
<td>24</td>
<td>18</td>
<td>10</td>
<td>22</td>
</tr>
<tr>
<td>Dwindling numbers</td>
<td>37</td>
<td>11</td>
<td>9</td>
<td>15</td>
</tr>
<tr>
<td>Practical problems</td>
<td>4</td>
<td>3</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>External organisations</td>
<td>9</td>
<td>9</td>
<td>6</td>
<td>9</td>
</tr>
<tr>
<td>Change of focus</td>
<td>5</td>
<td>11</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Never got going</td>
<td>7</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Achieved aims</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>Problems among members</td>
<td>4</td>
<td>2</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Merger</td>
<td>3</td>
<td>1</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Lack of support</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

*Columns add up to more than total of groups as categories are not exclusive.

The lifespan and life-cycle of self-help groups: a retrospective study of groups in Nottingham
Sarah Chaudhary, Mark Avis and Carol Munn-Giddings
Perspectives

‘Very often good ideas like peer support get picked up and officialised, and then lose a lot of the original value they had.’ (Ockwell C (2010) On the record. Mental Health Today May 38)

“Mutual aid can easily be destroyed by attempts to incorporate. The most effective interventions are likely to come through support for mediating organisations in the community and the creation of a ‘benign’ environment.”

MUTUAL AID AND SELF-HELP: Coping strategies for excluded communities (Burns & Taylor, Joseph Rowntree Foundation, 1998)

“Whilst professionals have become more aware of the value of self help groups, few understand the underlying principles of self determination and empowerment that contribute to the very life and success of these groups. By understanding these principles, we can have a better appreciation for how to form partnerships without compromising the essential nature of self help.”

Ed Madara, New Jersey Clearing House
One off self management interventions

- Good outcomes at completion
- Maintained at 3-6 months
- Some sustained at 12 months
- Little evidence of sustained changes beyond 12 months

(Jim Phillips, Quality Institute for Self Management Education and Training)
The National Evaluation of the Pilot Phase of the Expert Patients Programme – Final Report

“What outcomes might be relevant that were not predicted by the study design?

Establishment of social networks – reduction in social isolation a key outcome: Increases in social capital, social networks, reduction in isolation - valuing of effectiveness of group experience and follow-up”

National Primary Care Research & Development Centre, 2006

“In fact, a large number of the interventions that provide support for self care, even if their primary aim is not to create social networks, end up with the formation of groups.”

(Research Evidence on the effectiveness of Self Care Support, DH, 2007)
Group Members’ Experiences

“Belonging to a self help group has changed my life. I now have the confidence to get involved with things I would never have dreamed of!”

“It’s the emotional and practical support that makes the difference. People in the group understand what you’re going through and what it feels like. They have similar experiences and a wealth of knowledge and ideas.”

“It helps to talk to someone who knows what it’s like. Even your family can’t understand like people in the group do.”

“Making this journey alone would have been unbearable; travelling side by side with people who have walked this way before has been truly inspirational, healing me every step of the way.”

“I thought it was only me who was going through this but people in the group had similar stories to tell and similar experiences to mine. With their support and understanding I feel better about what to do and where to get help.”
A number of negative beliefs about self-help groups exist

Including concerns that groups are:

► harmful,
► anti-professional,
► addictive, and
► equivalent to the ‘blind leading the blind’

...all of which would lead to decreased support (Lee, 1995).
Mental Health Professionals' Support of Self-Help Groups (2001)

Hypothesis: professional support of self-help is influenced by the degree to which professionally-led groups are viewed as more helpful than self-help groups.

Results: Respondents who perceive professionally-led groups to be significantly more helpful than self-help groups were less inclined to support self-help groups through referrals, help in organizing groups, or financially.

Conclusion: To the extent that professional support of the self-help movement is diminished, valuable allies in the struggle to expand the reach of mental health services are lost.
<table>
<thead>
<tr>
<th>Individuals</th>
<th>Groups</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Severity and time since onset of problem</strong></td>
<td><strong>Type of focal problem</strong></td>
</tr>
<tr>
<td><strong>Personal beliefs</strong></td>
<td><strong>Ideology</strong></td>
</tr>
<tr>
<td>“embracing a status” Stiff upper lip, coping strategies. Denial</td>
<td>12 step programmes</td>
</tr>
<tr>
<td><strong>Culture</strong></td>
<td><strong>Leadership capabilities</strong></td>
</tr>
<tr>
<td>Different perspectives on the condition, stigma</td>
<td>Lay/professional</td>
</tr>
<tr>
<td><strong>Age and ethnicity</strong></td>
<td><strong>Cohesion</strong></td>
</tr>
<tr>
<td>“Do I fit” Are our concerns the same?</td>
<td>How well the group is working together</td>
</tr>
<tr>
<td><strong>Previous involvement in groups</strong></td>
<td>Common purpose, shared goals</td>
</tr>
<tr>
<td><strong>Level of life stresses</strong></td>
<td><strong>External networks and affiliations</strong></td>
</tr>
<tr>
<td><strong>Support network</strong></td>
<td>Links to other helpers</td>
</tr>
<tr>
<td></td>
<td><strong>Internal/external stress factors</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Resources</strong></td>
</tr>
<tr>
<td></td>
<td>People/money/information</td>
</tr>
<tr>
<td></td>
<td><strong>Member turnover, stability over time</strong></td>
</tr>
</tbody>
</table>
The Three Characteristics of Self Help

△ Common Experience and Resonance
Mutual aid is triggered not only by a common experience but also by similar feelings about that experience. The experiencing of reciprocal feelings by two people is called resonance. The identification is an important factor in the helping process as it enables the new member to feel less isolated, to face certain fears and to re-gain self-confidence.

△ Self Help is Essentially Free
Self Help/mutual aid is a voluntary activity, meaning that it is freely given and essentially free from charge. Mutual aid is exercised freely. In other words, it is not prescribed or demanded by authority or law neither is it controlled by organisations or institutions other than by the self help group themselves.

△ Equality
concerns the attitude and behaviours of members towards one another in responding to pain and to the consequences of suffering. .. accepting one another and behaving as equals by setting aside differences that are generally considered superficial and irrelevant to the mutual aid relationships.

Extracts from the Self-Help Way: Mutual Aid and Health by Jean-Marie Romeder. Published by the Canadian Council on Social Development, Ottawa, 1990
Common concerns

Lack of personal information about the group

- Rather than taking the more traditional route of making a formal referral, think about passing on contact information and signposting people to a group. Self help works best when individuals make an active and conscious decision to attend a meeting themselves.

- Most groups give an outline of their activities on their website or in the local self help or community groups directory and provide a telephone contact number for further details. Professionals can help by providing people with information on the nature of self help groups and, where needed, assistance with making enquires about the group before attending.
Common concerns

The group might offer medical advice

- The core activity of self help is mutual support, based on shared experience. The offering of medical advice is rare and discouraged. If medical advice is sought by members, the usual practice is for the group to refer the individual back to their G.P. or consultant. Today an extraordinary array of health advice and information is already in the public arena. The availability of health websites and health-related journals means that even the most discerning reader risks becoming confused or overwhelmed. Fortunately many groups have become skilled at assessing information, enabling members to avoid dubious or unsubstantiated sources.
Common concerns

The individual might find it difficult to be with people who are worse off than they are

• In practice, it is more usual for new members to find it helpful to meet longstanding members who are coping better with their condition because of their involvement in the group. Some meetings have sub-groups for people coping at a particular stage of their condition, for example young people with MS, so it’s worth checking this out first.
Concern: Joining might make an individual feel worse, not better

Self help groups are not designed for people in crisis or for those in need of emergency support or care. People go in a voluntary capacity and it would be highly unusual for someone to keep returning to a group that causes them further distress. Groups aren’t for everyone - people can choose to leave if they feel the group is not helping. Some people find they need to attend a number of meetings before they are relaxed enough to open up and talk to others. There’s nothing to stop someone going back to a group to try again. Most groups operate on an open or revolving-door basis.
Concern: People might become critical of conventional care

The majority of groups aim to work alongside professional services. Some actively encourage the involvement of health and social care professionals. A number of groups have used their own personal experiences to work in partnership with professionals to improve local services. The knowledge base built in groups, over time, can be quite different from that of an individual who has not had the same opportunity to share, reflect on and learn from others in the same situation.
Signposting to self help groups: guidance for professionals

• Keep groups informed - send relevant information to groups which they might otherwise not receive
• Talk to your colleagues; find out what they know about self help groups – if necessary put them right
• Become a self help champion – ‘talk up’ self help groups
• Use groups as a resource
• Invite groups to give a talk to your service
• Signpost people to groups
• Sign post groups to sources of help and support
Signposting to self help groups: guidance for professionals

• Educate yourself about self help
• Research the availability of local groups - particularly those which relate to your area of work
• Contact the groups and find out what they offer
• Sign up for their newsletter and literature, visit their website
• Offer to display their posters
• Visit the group (by invitation)
• Offer to give talks to groups
Identify the groups that might benefit the people you serve, and try to develop links. It is tempting to assume one knows what self help groups do and how their members benefit and yet many professionals have never visited a self help meeting. Those that have tend to be more positive about self help and more realistic about who might gain from getting involved in a group. Seek out a colleague or another professional, who has close and positive links with a group, and try to learn from their experience.

Most groups welcome interest, particularly from people who are keen to develop their understanding of self help, so it may be possible to attend a meeting. As a matter of courtesy, make contact with the group first, to check that a visit is acceptable to the members and convenient in relation to their activity calendar. Some groups (like AA) hold regular ‘open meetings’ when anyone can attend.
Promoting Mutually Beneficial Relations

Show an interest in the group and offer practical support
• offer to display their posters
• invite them to give a talk to your clients/service users
• ask them to send leaflets and posters
• ask to be put on their mailing list for their newsletter or programme
• offer to give a talk to the group

Go the extra mile
• If you are able, offer local groups a room in which to hold meetings or other ‘help in kind’.
• If you think the group is doing a good job, tell them and pass this message on to colleagues and other professionals.
• If you come across information that might keep the group abreast of new developments, pass it on to the group

Talk directly to groups
• If you are worried about an aspect of the group, raise it directly with the group concerned. Groups would prefer to know about such issues and are generally eager to open up a discuss problems or misunderstandings.
Most people benefit from having an opportunity to find out about the group and a realistic idea of what it can offer before they attend. Professionals may have a role to play here, in helping people to construct a list of questions before making an enquiry to a group. For instance:
how long has the group been going?
•what are the aims of the group?
•what sorts of things do you do in the group?
•is the group suitable for newly diagnosed people or have most of the members lived with their condition for a long-time?
•what is the gender/age/ethnic mix?
•is it possible to speak or meet with a member of a group before attending?
Figure 2: Ways of putting people in touch

Low intervention
- Displayed poster
- Told person group exists
- Gave person practical details
- Discussed likely pros and cons
- Invited group to meet clients
- Rang group - effected introduction
- Went with person to first meeting

High intervention
How can NHS bodies fulfil their role?

1. To link up with social care organisations and explore what voluntary and community sector resources and expertise are available.

2. To understand the available level of advice and the degree to which local groups can support self care. The most important aspect of this is to ensure that information can be easily shared throughout your area so that those who need it most can benefit.
Recommendations

PCTs, in partnership with Local Authorities should:

1. **conduct an annual mapping exercise of the support services available for individuals and their carers, including support groups**
2. **ensure that this information is proactively made available to people registered with an LTC and their carers, and**
3. **ensure that there is equity of access to these services across geographic and thematic groups.**

how groups create social capital

- **Recovery Capital** (resilience and empowerment)
- **Bridging Capital** (connection, networks and reach)
- **Linking Capital** (evidenced impact and voice)
- **Bonding Capital** (collective strength, reciprocity and mutual aid)

Self Help Groups
= Social Capital
“The closest the UK has to a national self-help support centre is Self Help Nottingham which is a specialist agency that has given back-up to self-help groups in Nottingham and surrounding areas. It maintains a database on local and national peer-support groups, provides practical support for local groups, training and networking opportunities and houses a collection of research relevant to self-help. “

Peer-Support Briefing, The SMART Recovery Project (Alcohol Concern, 2010)
We were funded by the DoH to develop an evidence based ‘toolkit’ to:

- develop a guide (the ‘Toolkit’) that will enable other areas to recreate what Self Help Nottingham achieve in Nottinghamshire - a known, used and supported self help group sector
- create the learning and evidence based approaches that will enable Self Help Nottingham to support areas to develop their own self help group service to enhance local capacity for self care

We have achieved this by combining the expertise of Self Help Nottingham with the learning from implementation in pilot areas in the West Midlands
Draft integrated care model for East Leicestershire and Rutland

**HERA SUS** → **Risk Stratification Tool** → **Clinical judgement used to supplement the risk stratification tool**

The Co-ordinator/Team will identify patients from medium to high risk

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The Multi-Disciplinary Team may consist of any of the following according to patient needs:
- GIP
- Social Care
- Mental Health
- MacMillan
- Geriatrician
- OT
- Specialist Nurse Teams
- Specialist Nurses
- Physiotherapists
- Intermediate Care Teams
- Mental Health Services for Older People
- Allied Health and Social Care Professionals
- Pharmacists

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**Multi-Disciplinary Assessment & Service Delivery Team**
The MDT will conduct joint assessments

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**Identified patients**

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**Co-ordinator**
(Point of access)
The co-ordinator will assess, review and care plan before moving onto the MDT

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**Optimise**
Self-Help Groups
Care
Telehealth

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1 New post/role
2 Active review team member
How it works in practice

• Pairs people who are about to undertake a particular treatment with someone who has already experienced it
• Have a "register" of men who are prepared to talk on the phone with Newly Diagnosed Men about their experiences, ideally whilst the NDM are considering their treatment options
• Whilst the Support Group maintains the register, it's administered by the Specialist Nurses in Urology at the City.
• It's the Nurses who assess whether any NDM going through would benefit from speaking with a Buddy
• I wish we could claim 100% take up, but unfortunately not all NDM would be candidates for "Buddying": we don't have Buddies available for every condition and treatment option: some men remain too traumatised to rationalise the offer: some men simply choose not to follow up on the offer
• We still get feedback that some newly diagnosed men aren’t aware of our Buddy system. We know through our meetings with the Nurses that the information is certainly always provided at time of diagnosis, but sometimes not absorbed as there maybe stress induced information overload

Colin Boulter, Nottingham Prostate Cancer Support Group, established 2005 with assistance from Self Help Nottingham
Closing the loop and capturing feedback – sharing stories

Patients and carers are increasingly asked to give feedback about recent healthcare experiences, online and often in public, through web sites such as Patient Opinion, NHS Choices, or I Want Great Care.
Feedback from Mental Health self help groups Network Event Sept 2012

• something needs to be added to inform patients that they have the right to bring someone with them to any appointments. This is important for people that are unwell and may be unable to understand the choices/options on offer.

• Suggested a Q.4) Where can I find a local self help group for this condition?

• Some felt the word OPTIONS may not be ideal as CHOICE was a preferred word that everyone understands and uses. Also PROs and CONs is not plain English – maybe Good and Bad – or Advantages and Disadvantages would be better.

• When you open the leaflet – there is so much to read it seems very muddled. “…the waffle in the middle is very confusing…”

• Where it talks about support available the types of support you can expect professional (clinician), group therapy, voluntary sector organisations, peer-support, self help groups (including information about self help groups).

• Many were not clear about the content of the leaflet, some said they wouldn’t pick it up unless it was given to them.

• Generally the members were very interested and glad to see a shift in how information and choice is presented to patients in the NHS.
“The key components of SDM identified by NHS staff (PART 2):

• health professionals who have the necessary communication and information sharing skills, and who **genuinely respect** patients/services users’ knowledge and expertise within decision-making processes”

Supporting Shared Decision-Making: A PATHFINDER PROJECT FOR NHS NORTH WEST, (Picker Institute Europe, 2011)
Asset Based Community Development – as easy as ABCD?

- Currency of content is king, classification is tricky
- Some groups exist despite services, or in direct response to perceived gaps and like independence
- Ownership = empowerment
- Not an expendable asset
- Think not what self help groups can do for you, but what you can do for self help groups
- If you want them to ‘keep in touch’, you need to help them ‘keep up the good work’
- New members are the lifeblood of groups
Information: first line *therapy*?

Source: Salford’s Primary Care Commissioning Strategy 2007/08 – 2017/18
Power of Information (21 May 2012)

“Information regarded as a health and care service in its own right for us all – with appropriate support in using information available for those who need it, so that information benefits everyone and helps reduce inequalities” (Main ambitions)
The problem of non-adherence

WHO report on non-adherence

- Estimated that over 30 -50% medicines prescribed for long term illnesses are not taken as directed

- If prescription was appropriate then this represents a loss for patients and for the health care system

- NICE estimates £2.7-£4Bn
"Our greatest challenges have come from the statutory sector where our informality and lack of bureaucratic controls seem to be viewed as dangerous."

“To displace control as a means of regulating working practices requires the development of trust as a means of dealing with uncertainty and ensuring that those involved in co-operative work behave appropriately.

Trust—in the sense of the ‘expectations held by one party that another will behave reliably and predictably’ - can take a number of forms which can substitute for control in providing a basis for collaborative working. Trust may have various foundations, from initial knowledge of the other party’s reputation to the trust found in long-term reciprocal relationships, but the more resilient and robust forms of trust take considerable time to develop”

‘Patients as team members: opportunities, challenges and paradoxes of including patients in multi-professional healthcare teams’
Graham P. Martin and Rachael Finn, Sociology of Health & Illness Vol. 33 No. 7 2011, pp. 1050–1065
Engagement = Dancing the ‘awkward dance’

“I’m afraid you misunderstood. ... I said I’d like a mango.”