

## The contribution of self-help/mutual aid groups to mental well-being

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### What is known about this topic

- Self-help/mutual aid groups are associated with increased self-esteem and ability to cope, and decreased isolation.
- Supportive relationships and giving to others increase mental well-being.
- Current approaches to promoting well-being overlook the potential contribution of self-help/mutual aid groups.

### What this paper adds

- Evidence that self-help/mutual aid groups can make a strong contribution to mental well-being.
- Qualitative evidence about how 21 self-help/mutual aid groups promote mental well-being.
- Suggested measures relating to funding and evaluation to increase the contribution of self-help/mutual aid groups to mental well-being.

### Abstract

This article explores the contribution of self-help/mutual aid groups to mental well-being. Self-help/mutual aid groups are self-organising groups where people come together to address a shared health or social issue through mutual support. They are associated with a range of health and social benefits, but remain poorly understood. This article draws on data from stage one of ESTEEM, a project which runs from 2010 to 2013. Stage one ran from 2010 to 2011 and involved participatory, qualitative research carried out in two UK sites. Twenty-one groups were purposively selected to include a range of focal issues, longevity, structures and ethnic backgrounds. Researchers carried out 21 interviews with group coordinators and twenty group discussions with members to explore the groups' purpose, nature and development. Preliminary analysis of the data suggested that mental well-being was a common theme across the groups. Subsequently the data were re-analysed to explore the groups' contribution to mental well-being using a checklist of protective factors for mental well-being as a coding framework. The findings showed that groups made a strong contribution to members' mental well-being by enhancing a sense of control, increasing resilience and facilitating participation. Group members were uplifted by exchanging emotional and practical support; they gained self-esteem, knowledge and confidence, thereby increasing their control over their situation. For some groups, socio-economic factors limited their scope and threatened their future. The article provides an evidence-base which illustrates how self-help/mutual aid groups can enhance mental well-being. If supported within a strategy for social justice, these groups enable people with varied concerns to develop a tailored response to their specific needs. The authors suggest that policy-makers engage with local people, investing in support proportionate to the needs of different populations, enabling them to develop their own self-help/mutual aid groups to enhance their sense of mental well-being.

**Keywords:** mental health, mental health promotion, mutual aid, participation and empowerment, peer, self-help group

## Background

### Self-help/mutual aid groups

This article explores the contribution that self-help/mutual aid groups make to mental well-being. We focus on groups with a health or social care focus where people with a shared problem or experience come together for mutual support (Wilson 1994, Elsdon *et al.* 2000). These groups are organised by their members who often choose to pursue wider interests including education and campaigning (Adamsen & Rasmussen 2001). To emphasise the role of mutuality we follow Munn-Giddings & Borkman (2005) in combining the terms 'self-help' and 'mutual aid':

Because it is the combination of self-responsibility with the reciprocity (mutuality) of relationship with others and the consequent processes within the groups that helps the individuals to help themselves. (p. 140)

Self-help/mutual aid groups can be distinguished from professionally led support groups by their experiential knowledge and peer reciprocity, enabling members to both give and receive holistic, empathetic support (Munn-Giddings & McVicar 2006). Mutuality replaces dependency on professional care. As they share their experiences, group members may replace pathological explanations of their situation with more positive interpretations which take account of the wider context (Borkman 1999). Research suggests that group membership is associated with a range of health-related benefits including improved health outcomes and more efficient use of health and social care services (Kryouz *et al.* 2002, Pistrang *et al.* 2008); increased self-esteem; improved relationships; better ability to cope and decreased levels of isolation (Gray *et al.* 1997).

The number of self-help/mutual aid groups is rising (Munn-Giddings & McVicar 2006), taking many different forms. Borkman & Munn-Giddings (2008) find that the way relationships between the healthcare system and the voluntary sector are framed in each country impacts on the nature of self-help/mutual aid, mirroring differences in consumer participation. Confirming this, Munn-Giddings & Stokken (2012) refer to the 'Scandinavia model', which positions self-help/mutual aid groups in a consensual relationship with statutory services, often involving facilitative and financial support. Similar groups in the USA have historically adopted a more conflictual relationship in opposition to statutory provision. Within the UK there is a spectrum of groups labelled differently but with overlapping char-

acteristics (Seebohm *et al.* 2010). 'Peer support group' appears to be the preferred label for self-help/mutual aid groups in the mental health field. In the UK, mental health 'user groups', self-organising groups of people using mental health services, often include self-help and social support functions (Wallcraft *et al.* 2003), but arguably can be distinguished from self-help/mutual aid groups by positioning themselves alongside services. There remain relatively few UK studies of self-help/mutual aid groups (Chaudhary *et al.* 2010). Our focus on groups excluded individually focused self-help activities.

### Well-being

Well-being is a popular political goal, especially in the UK where economic policies failed to increase quality of life (Wilkinson & Pickett 2009) and unsustainable healthcare costs encourage health promotion strategies (Department of Health 2004). The UK government defines well-being as 'a positive physical, social and mental state' (Department of Health 2010, p. 14) which it seeks to promote through a range of policies including cross-government strategies (Department for Work & Pensions & Department of Health 2008) and inter-agency Health and Wellbeing Boards across England (Department of Health 2010, 2011). Some of these policies, particularly in relation to welfare, have attracted criticism. Edwards & Imrie (2008, p. 338) identify a 'moral discourse' linking well-being with personal responsibility. This emphasises individual self-help and clinical therapy as interventions to get people with a disability into work, taking the focus away from socio-structural barriers and human rights. Taylor (2011) agrees that the emphasis on individual self-help is too narrow and calls for welfare policy to recognise the social nature of humans. Others argue that well-being policies must be grounded in social justice (e.g. Friedli 2009, Coote with Goodwin 2010, Marmot 2010).

We draw on the concept of 'mental well-being', often used interchangeably with 'positive mental health' from the literature of mental health promotion. Mental well-being combines how people *feel* about themselves and their life with how they *function* in their relations with others and in pursuit of their aspirations (Friedli 2009, Scottish Government 2009). It cannot be equated with the absence of mental ill-health: people with a diagnosed mental health problem can enjoy mental well-being and fulfilment in life (Department of Health 2010) and conversely, those who have no such diagnosis may feel overwhelmed by daily pressures. Socio-economic and

environmental factors play an important role in determining mental well-being, but the circumstances of our lives are not the only factor; it is 'how we as individuals interpret and respond to those circumstances' (Mental Health Foundation 2011, p. 3). The Health Education Authority defines mental health or well-being as:

The emotional and spiritual resilience, which enables us to enjoy life and survive pain, disappointment and sadness. ... an underlying belief in our own and others' dignity and worth. (Health Education Authority 1997, p. 7)

Recent reports on well-being suggest that good relationships help to instil this resilience (e.g. Friedli 2009). Global evidence of interventions that promote mental well-being were reviewed by the Foresight Mental Capital & Wellbeing Project (2008) which commissioned the think-tank, new economics foundation, to distil this into 'Five a Day' actions that benefit everyone:

- 'Connect
- Be active
- Take notice
- Keep learning
- Give'. (Aked *et al.* 2008, p. 3)

Examples include joining a community group, having a range of relationships, taking up exercise or dance, being interested in others, reflecting on personal experiences and learning of any kind. Helping, sharing, giving and offering support to others contribute to mental well-being (*ibid.*). In turn, mental well-being influences many beneficial outcomes:

Healthier lifestyles; better physical health; improved recovery from illness; fewer limitations in daily living; higher educational attainment; greater productivity, employment and earnings; better relationships with adults and with children; more social cohesion and engagement and improved quality of life. (Friedli 2009, p. III)

Those seeking to promote mental well-being can draw on a 'toolkit for commissioners', which suggests appropriate strategies and interventions (Newbigging & Heginbotham 2010), an 'impact assessment toolkit', which provides a process for assessing the impact of a programme on well-being (Cooke *et al.* 2011) and a 'mental well-being checklist', based on the impact assessment toolkit, which provides a 'quick framework' to help people consider mental well-being when commissioning, delivering or developing initiatives [National Mental Health Development Unit (NMH DU) 2011, p. 1]. All three documents stress that factors enhancing mental well-being differ across social, economic and cultural settings so strategies should ensure equity across social groups. What works for older people may not work for the young.

People from collectivist cultures tend to prioritise their obligations to family and society (Fernando 2010), interdependence and harmony (Newbigging & Bola 2010), whereas those from individualistic cultures may emphasise control (*ibid.*) and emotions (Fernando 2010). Newbigging & Heginbotham (2010) argue that while people recovering from mental ill-health may be prioritised for mental well-being interventions, it is cost-effective to invest in interventions for the broader group of people deemed at risk of distress and indeed for the population as a whole. To identify and develop an appropriate range of interventions, they and others recommend that authorities engage and work with their communities (*ibid.*; Coote with Goodwin 2010, Cooke *et al.* 2011).

Like Friedli (2009) and others, the toolkits emphasise the centrality of social justice, the need to take into account wider socio-economic and environmental determinants and balance personal responsibility for mental well-being with collective responsibility and interdependence. Although the literature on mental well-being refers to participation, community action and empowerment there is no specific mention of self-help/mutual aid groups, a gap we wish to address.

### Purpose of the paper

Our purpose here is to explore the contribution of self-help/mutual aid groups to mental well-being, using the NMH DU checklist (2011) as an authoritative framework to support our analysis. Core protective factors for mental well-being are categorised under three headings:

- Enhancing control.
- Increasing resilience and community assets.
- Facilitating participation and promoting inclusion. (NMH DU 2011)

Up to 11 sub-categories are listed under each of these headings, operating at an individual or community level. These tend to overlap, reiterating the importance of good relationships and networks. This checklist, with all headings sourced by the NMH DU checklist, can be found in Table 2 (under Findings). The checklist also asks if wider socio-economic and environmental determinants are being considered and if the intervention is equitable for all social groups.

## Methods

### Background

This research is part of a Big Lottery-funded project, ESTEEM, which involves Anglia Ruskin University,

Nottingham University and Self-Help Nottingham, a specialist charity supporting self-help groups. ESTEEM is being carried out over three stages from 2010 to 2013 to develop guidelines for health and social care professionals on how to support self-help/mutual aid groups. The research is not yet complete, but this article draws on data from stage one, carried out from 2010 to 2011. Ethical approval was given by the Research Ethics Committees at Anglia Ruskin and Nottingham Universities, and the research was carried out in two sites: Essex and Nottingham.

### Design and methods

ESTEEM adopted participatory action research (PAR) principles: PAR is 'the study of a social situation carried out by those involved in the situation in order to improve both their practice and the quality of their understanding' (Winter & Munn-Giddings 2001, p. 8). Participants, professionals, commissioners and others came together to plan and review the research. Qualitative methods were chosen to help the researchers understand the groups from an insider perspective (Denzin & Lincoln 2005).

The criteria to include groups in the sampling frame for stage one were the four characteristics often described as essential features of self-help/mutual aid groups:

- Members share an experience or problem.
- Members come together for mutual support.
- Members control and own the group.
- Membership is voluntary. (Wilson 1994, Elsdon *et al.* 2000)

We identified groups which primarily focused on mutual support; whether or not they also pursued social or service change was not taken into account at this stage. Member-led control excluded groups managed by professionals or constrained in their format or activities by funders or statutory services. We included no groups fitting prescribed models such as the Alcoholics Anonymous Twelve-Step programme. Attendance at group activities had to be voluntary rather than required as part of a rehabilitation or recovery programme.

Self Help Nottingham had a local database of 202 suitable groups for the Nottingham sampling frame, but in Essex researchers had to draw on many databases, websites and professional contacts to achieve a sampling frame of 24 groups. The final sample of 10 groups in each site was purposively selected to include the following:

- A range of health and social issues.
- Established and new groups (under 3 years old).

- Affiliated and independent groups.
- Groups run by and for people from black, Asian and minority ethnic (BAME) communities.

All selected groups agreed to participate except one where members felt they did not need outsider support making ESTEEM irrelevant, but their coordinator agreed to be interviewed and a further group was successfully invited. Therefore, with limited data from one group there was a total sample of 21 groups. Information sheets were sent to groups in advance then explained by researchers verbally, using interpreters where necessary prior to requesting written consent. All participants gave written informed consent. Anonymity was assured and for this reason groups are numbered 1–21 in the Findings without reference to site or focus.

Three researchers (first three authors) collected data in Essex and Nottingham from June 2010 to February 2011, carrying out 21 semi-structured interviews of 45–120 minutes with group coordinators and 20 group discussions of 45–90 minutes with members. Coordinators were identified by their groups and group discussion participants were self-selected. Interviews and discussions were taped and fully transcribed except where groups preferred written notes ( $n = 5$ ). Questions covered the groups' purpose, ethos, activities, achievements, challenges and external relationships. A preliminary thematic analysis was carried out and an overview of early findings is reported elsewhere (ESTEEM Project Team 2011). Subsequently, the research team decided to explore the contribution of the groups to mental well-being and for this purpose, the first author re-analysed the 41 transcripts. The NMH DU (2011) mental well-being checklist (Table 2) provided a coding framework for a 'directed approach' to content analysis whereby researchers draw coding categories from existing theory (Hsieh & Shannon 2005, p. 1277). Data that could not be coded were identified creating categories not listed by NMH DU (see Discussion). This enables a directed approach to support or extend existing theory. Data were managed on Nvivo software (QSR International Pty Ltd, Doncaster, Victoria, Australia).

## Findings

### Overview

The findings begin by describing the participating groups and members' experiences prior to joining their group. Data are then grouped under three headings (in italics): enhancing control, increasing resilience and facilitating participation. Under each of the three head-

ings are sub-headings (numbered) from the checklist (Table 2), but sub-headings are aggregated or omitted where there is little or no corresponding data. Limiting factors affecting the groups' capacity to increase mental well-being are described before a concluding section summarises the findings. This analysis does not distinguish between factors operating at an individual or community level for lack of space.

**Participating groups**

Participating groups focused on a wide range of issues including life-threatening to chronic physical ill-health (*n* = 10), mental ill-health (*n* = 5) and socially isolating situations (*n* = 6) (Table 1). Four groups were of people from specific ethnic minority backgrounds.

This demarcation was not precise: most health-focused groups also sought to reduce their members' isolation, and socially isolated groups discussed health issues. Group size varied as follows: one that was struggling to survive had only three regular members, but some had over 30. Groups met in cafes, community-based and hospital rooms. Most meetings were informal, but a few groups preferred more formal arrangements. Many welcomed family members. Most groups were set up by members, often supported by professionals. Most groups for people from BAME backgrounds received more organisational help than others from within their own community.

**Experiences prior to the group**

Many participants referred to their isolation, loss and fear caused by a new life-threatening or chronic health problem, or a child with severe behavioural problems:

It affects them emotionally, it affects them spiritually, it affects them financially and socially. (Group 2)

**Table 1** The focus of participating groups

Physical ill-health ( <i>n</i> = 10)	Mental ill-health ( <i>n</i> = 5)	Social isolation ( <i>n</i> = 6)
Aphasia (1)	Diagnosis specific (2)	Chinese people (1)
Arthritis (1)	General (1)	Gay men (1)
Cancer (2)	South Asian women (1)	Parents of children with autism/learning difficulties (2)
Diabetes (2)	Women only (1)	South Asian women (2)
Drugs & alcohol (1)		
Epilepsy (1)		
Myalgic Encephalomyelitis (ME) (1)		
Vertigo (1)		

Many lacked hope: 'lots of people just think that's it, stop, this is as far as I can see ahead' (Group 5). Clinical processes, some said, exacerbated their sense of losing control and identity. Participants with Myalgic Encephalomyelitis (ME), alcohol problems and Type 2 diabetes reported that many (but not all) GPs lacked interest and expertise. Participants with chronic health or family problems often lacked support and information: 'you're just left stranded' (Group 11). People from South Asian and Chinese communities were often isolated because of language and cultural barriers. Those who became depressed or disturbed might remain within the home and so be isolated further.

**Enhancing control**

*Sense of control*

Many participants suggested that member control was essential to their groups' success:

The notion of self-help is about control of the group ... unless the control of the group is entirely within the group's hands it isn't quite the same thing. (Group 15)

Professionally run groups, some said, served a purpose, but many felt that their role and impact were limited compared with member-led groups: 'We put it on ourselves so it's what we want' (Group 19). They emphasised the absence of rules and bureaucracy, finding that informality and 'what works' for the group were what mattered. The voluntary nature of joining and leaving was central to the groups' appeal and success. Members took and gave back what they chose. Compulsion, they said, would have destroyed the positive impact of helping themselves and others:

It's something that isn't compulsory ... you probably have to see your [consultant], and you probably have to comply with drug treatment, but it's important that the group remains a voluntary thing. (Group 1)

Coordinators of some BAME groups said that many members lacked English literacy and leadership skills, but involvement and a strong sense of group ownership developed over time. In all groups, the members enjoyed having a say in what happened, but many preferred to leave funding and organisational matters to their coordinator.

*Self-belief, self-determination, ability to make healthy choices*

Many participants described how sharing experiences and knowledge enabled them to start rebuilding their lives. Emotional relief created space for thinking about the future. Sharing stories, many felt, enabled members to recognise their own and others' expertise.

They shared tips about drug therapy, surgical interventions, side-effects and living well:

What is really important in your treatment but also what you can get away with ... you've still got to live in the real world. (Group 12)

Members 'give you a different angle or a different idea or a different way to look at something' (Group 19), extending knowledge about available options:

I normally use the analogy of a sweet shop, you've got lots of different flavours and we all have a different palate and ... when you have peers who've been through a similar journey as you, and you hear about flavours, you think ah, I've never tried that flavour, well that sounds quite nice, I'll give it a try. It opens up your horizon. (Group 2)

In subtle ways, members came to see themselves in more positive ways, fostering self-belief and optimism. People with ME felt validated as their problems were acknowledged and shared: 'that gives you strength to think, well, it isn't in my head' (Group 6). South Asian women, who had been shunned and shamed gained confidence and moved into new roles:

Another lady who had gone through an episode of domestic violence ... so she had a lot of shame ... now she is our regular tutor ... and she has such a big pride. (Group 9)

Thirteen groups invited speakers including consultants, dieticians and private health providers to increase members' knowledge of their conditions, treatment options and services. They disseminated information through newsletters, DVDs, websites and books. Some members chose not to attend meetings, but valued and accessed the groups' information resources. Groups accumulated knowledge regarding local resources and practical matters including travel, legal aid and welfare benefits, and signposted members when appropriate. Most groups aimed to offer members 'insight into what they're dealing with, what the future may hold, what's available to them now' (Group 8) to help them look after themselves:

I've learnt more about epilepsy in three hours than I have in 30 years. (Group 13)

Consequently, some participants said, they became more confident and informed when dealing with their GP or consultant, increasing access to treatment of their choice.

#### *Opportunities to influence and be heard*

Many groups sought to increase awareness and reduce stigma as members took what they learnt in the groups to their family and friends or organised public displays at events, libraries, supermarkets and elsewhere attracting considerable interest:

We've got our own display which I can chug around to anywhere. (Group 5)

Many group members had views about how clinical practice might be improved, but they were often not well enough to participate in consultation processes. Some groups did get involved, joining campaigns or consultations although this was not their central purpose. More often individual members attended meetings on behalf of the group:

I feel like I can speak up ... and I can do something about it. (Group 1)

#### **Increasing resilience**

##### *Emotional well-being; ability to function socially*

Many participants spoke of being 'uplifted', getting a 'boost', feeling 'perkier', gaining energy and strength from attending their group: 'you walk out feeling positive' (Group 7). Meeting others in similar circumstances and offloading their problems to people who understood and accepted them made members feel less isolated and more hopeful:

Being able to talk to somebody else in a similar situation lightens the load internally. (Group 2)

Many participants observed how confidence grew as a result of involvement in the groups. People who had been shy started to speak up about their situation inside and then outside the group: 'it's empowerment' (Group 5). Some came to see themselves differently, more positively and holistically than their label of 'alcoholic', 'cancer sufferer,' or 'depressed'.

Participants spoke of enjoying meetings, celebrations, fund-raising activities and trips. Many spoke of laughter and relief from tension:

I don't think any of us had laughed so much, we really enjoyed that [speaker] – so we are not just a group that talks about arthritis ... I've found that very helpful. (Group 14)

##### *Learning and development*

Several members gained skills, from computers to crafts, participated in the arts or took on new roles. Some BAME groups helped members to access English language tuition. Most, but not all groups were grounded in their community linking members with activities, resources and festivals. For some, getting involved in their group was part of a recovery process:

A step further to coming back into the big wide world and getting a job. (Group 4)

We can give confidence to each other ... [other members] make you feel like getting out of bed when you don't feel like it. (Group 20)

#### *Healthy lifestyle*

Most groups promoted a healthy lifestyle, exercise and diet at or outside their meetings, including access to complementary therapies, walking groups, women-only swimming and safe sex aids. Older Chinese people felt emotionally uplifted and mentally alert as they danced. South Asian women went salsa dancing:

[We] started to do a wide variety of activities, exercise classes, even salsa classes ... we have walking groups. (Group 20)

#### *Trust and safety, social networks, relationships, emotional support*

Groups were described as safe places where members felt cared for: 'you feel cocooned and it's nice' (Group 6). Here, participants felt that they could talk in confidence, essential for BAME and other groups based within closely knit communities:

A refuge from the nitty gritty of the wider world and from the white coats and note-takers. (Group 4)

Here you feel confident – no one will go and talk to some other person. (Group 18)

Participants distinguished the unique emotional support provided by groups from family support. One-to-one support was occasionally available, but most was reciprocal. Established members supported new arrivals, who later supported others. Some had counselling experience, but it was the empathy and warmth that mattered:

Hugging, that's what we want! (Group 2)

It feels as though the group bears each other's burdens. (Group 4)

Many participants continued to support each other outside group meetings, getting together for a chat, walk or trip. Some communicated through text messages, Facebook, e-mail or telephone. Members struggling to cope with their situation or with a clinical appointment could call on others who understood:

We've always got that constant support there. (Group 19)

Larger groups formed loose networks. Relationships were sometimes purposeful to gain information rather than emotional support, but overall they were informal, relaxed and helpful. Smaller, stable groups tended to have close bonds:

We help each other ... we laugh and we joke ... and we love each other. (Group 3)

#### **Facilitating participation**

##### *Valued roles*

Many participants spoke of valuing their group involvement. They wanted to give back the help that they had received, to prevent people having the poor clinical experiences that they had, or to help their community: 'it was a sense of vocation' (Group 13). Giving was as important as receiving help. Many members helped in simple ways such as organising refreshments or sharing personal experiences. Coordinators held mentally and emotionally demanding, time-consuming responsibilities: 'it's a huge amount of time, you've got to have the passion to do it' (Group 21). Their reward was to know that they made a difference to people's lives, through feedback from members and their visibly improved health or happiness:

[Peter's] dizziness meant he virtually would not leave his home – eventually the group got him to go on a trip to Cadbury World and since then he's a different man. (Group 16)

Something's working here, I love it all, to see it all ... I think, wow, this is part of what happens in the group ... that's my payback really. (Group 21)

##### *Sense of belonging, being involved*

For some participants, group meetings were a highlight they rarely missed. The shared ownership, experiences and warmth created a sense of belonging or, as participants from five groups said, a 'family'. They encouraged and looked out for each other:

We're like one big family there to support each other. (Group 19)

Three BAME groups operated more like extended networks, respected within their community, while a South Asian mental health group remained small and discrete.

#### **Limiting factors**

The capacity of groups to contribute to mental well-being was sometimes limited by economic, social or structural factors. Funding was a frequent problem. Small amounts of funding were often needed for venues, transport for members with a disability and publicity, but could be difficult to find. People from the most disadvantaged sectors of society, including

some BAME, drug and alcohol and mental health groups, feared their group would end for lack of funding. At least three coordinators relied on financial support from their family or used their personal resources to fund group activities. Many participants felt that funders demanded inappropriate structures and monitoring, so a few groups sought to be self-sufficient:

That's a problem with funding – [funders] expect a certain structure and that could take a group in a direction it didn't particularly want to go. (Group 15)

Many groups wanted assistance with fund-raising and practical matters, especially where there was no specialist support for self-help groups. Community Voluntary Services (CVS) organisations provided affordable venues and advice to a few groups, but others did not know them, need them or felt they did not serve small groups. Community development workers supporting two BAME groups were made redundant. Group coordinators were often unwell due to their condition and some would have liked more help than members could provide. Eight groups were affiliated to national charities to get support and status. Relationships varied from inspirational to indifferent or worse for three groups who found that their national charity failed to appreciate the group's voluntary ethos:

It's almost as if we're not allowed to say or do as we please ... almost as if we're only there to raise funds for them. (Group 13)

Participants often complained about the relationship between their groups and the statutory sector. GPs were sometimes criticised for their lack of interest and for failing to inform their patients of groups which might have helped them, limiting the groups' ability to recruit new members. Health professionals were sometimes warm and helpful, but others could be remote:

It's very difficult to get a relationship with the [health trust], they're just not available. (Group 1)

### Summary of findings

Across a varied sample of self-help/mutual aid groups there was remarkable consistency in their data. Prior to joining the groups many participants seemed at risk of mental ill-health, while participants of five groups were likely to have a diagnosed mental health problem. Much of the data suggested that the groups improved mental well-being (see Table 2), benefiting individuals and creating community-based resources. Participants controlled group activities, gained self-esteem and knowledge, enhancing scope

for self-determination and choice. They became uplifted through enjoyment, supportive relationships, learning and personal development. Giving was important, helping members to gain a sense of belonging and being involved. The BAME groups were, like other groups, tailored to their specific needs and most enabled members to increase their connections with the wider community. Social and economic factors limited the scope of some groups, who wanted more help with practical and funding matters.

There was no data relating to a small number of checklist sub-categories including job control, the economy and conflict resolution because these were beyond the scope of participating groups.

### Discussion

Overall, the NMHDU (2011) checklist proved useful for our purposes, showing that participating groups made a strong contribution to mental well-being under all three categories of enhancing control, increasing resilience and facilitating participation (see Table 2). Hatzidimitriadou (2002) found that the balance of benefits differed for members of different groups according to their emphasis on personal or social change; we had insufficient data to comment on this. We found the checklist failed to anticipate the importance of reciprocity and mutuality, unlike the Foresight Mental Capital & Wellbeing Project (2008) evidence-base referred to earlier which identifies 'giving' as a way of promoting well-being (Aked *et al.* 2008). Reciprocity distinguishes peer-to-peer relationships from the unequal relationships between professional and patient (Mead *et al.* 2001). Peer support in mental health settings has been promoted in recent years but tends to be on a one-to-one basis between patients and peer support workers (Faulkner & Bassett 2012). There is a further step to be taken before statutory authorities promote peer support in member-led groups where control is no longer in the hands of management. Our data suggest that the gulf between groups and professionals, described as 'two worlds' by Wilson in 1994, sometimes persists. As the ESTEEM study continues, we find the sharing of experiences within self-help/mutual aid groups sometimes causes concern to medical practitioners, confirming earlier literature (Wann 1995). Yet our data here suggest that sharing experiential knowledge and mutual support enables group members to think differently about their situation, take control over their lives and move on. Agency and self-esteem replace passive and pathological attitudes, as Borkman (1999) suggests.

**Table 2** Checklist of protective factors associated with well-being and contribution from participating self-help/mutual aid groups

Enhancing control	Increasing resilience and community assets	Facilitating participation and inclusion
Individual Level		
✓✓✓A sense of control	✓✓✓Emotional well-being	✓✓✓Having a valued role
✓✓✓Belief in own capabilities and self-determination	✓✓✓Ability to understand, think clearly and function socially	✓✓✓Sense of belonging
✓✓✓Knowledge, skills and resources to make healthy choices	✓✓✓Have beliefs and values	✓✓✓Feeling involved
Maintaining independence	✓✓✓Learning and development ✓Healthy lifestyle	
Community/organisation level		
✓✓✓Self-help provision	✓✓✓Trust and safety	✓✓✓Activities that bring people together
✓✓✓Opportunities to influence decisions	✓✓✓Social networks and relationships	✓Practical support
✓✓✓Opportunities for expressing views and being heard	✓✓✓Emotional support	✓Ways to get involved
Workplace job control	Shared public spaces	Accessible and acceptable services
✓✓✓Collective organisation and action	Sustainable local economy	Cost of participating
Resources for financial control and capability	✓Arts and creativity	Conflict resolution ✓✓✓Cohesive communities

Code: ✓✓✓, strong contribution; ✓, some contribution.

The member-led nature of self-help/mutual aid groups did not stop them wanting support to address social and economic barriers to development: most groups were set up with professional help and wanted greater recognition from health services. Taylor *et al.* (2007) found that small community-led groups often valued a range of support including confidence-building, critical friend, broker and someone to turn to in a crisis. As our data suggested, they found that historically disadvantaged groups wanted more support than others. Foresight, in their advice to policy-makers on well-being state:

It will be important for different parties to work together in concert. Overall, it will be crucial to be clear about the balance of action. (2008, p. 11)

It can be hard for experienced community workers to get the right balance between being 'on tap, not on top' (Seebohm & Gilchrist 2008) and as Wilson (2009) pointed out, health professionals are not trained in community work skills; they may be ill-prepared to relinquish control. Wilson recommended more investment in intermediary organisations such as CVS, but current cut-backs in public funding means scarce resources increasingly focus on front-line services. Groups appear to be a cost-effective resource and ideally this would be measured, but this would be difficult in such informal, often intimate settings. Groups felt that formal monitoring or evaluation would threaten their informal ethos, but participatory approaches to research may be feasible and acceptable for some groups.

The groups catered well for a range of social groups including people with BAME backgrounds. The UK government has expressed concern that separate provision for specific ethnic groups fosters social fragmentation (Commission on Integration & Cohesion 2007), but research with BAME communities concludes that many distressed and vulnerable people want to recover in settings where their specific socio-cultural issues can be addressed (Rai-Atkins *et al.* 2002, Kalathil *et al.* 2011).

### Limitations

As mental well-being was not the focus of the main study, participants were not explicitly asked about it. Consequently, some participants might describe the protective factors differently and Table 2 is based on researchers' views.

### Policy implications

Policy-makers, the UK's Health and Wellbeing Boards and professionals can promote mental well-being by fostering the growth of self-help/mutual aid groups. However, they must appreciate that top-down control including compulsory attendance or monitoring requirements threaten the voluntary, member-led ethos that underpins the groups' success. Similarly, interventions for mental well-being cannot be shaped from above: community engagement and infrastructure support for community-led initiatives could help to ensure self-help/mutual aid groups and other

community-led initiatives meet local needs (Visram *et al.* 2012). Marmot's notion of 'proportionate universalism' whereby interventions are implemented for different groups 'with a scale and intensity proportionate to the level of disadvantage' (2010, p. 16) affirms the principle of higher investment for historically disadvantaged groups to ensure social equity. Groups are not for everyone, but a range of specific and inclusive self-help/mutual aid groups could benefit many people. Investment in participatory research could explore ways of assessing the cost-effectiveness of this approach.

### Conclusions

Self-help/mutual aid groups have a low profile, are little understood and do not fit easily within a regulated health sector. This article helps to address this lack of recognition of their potential by providing an evidence-base, which illustrates how they can enhance mental well-being. In brief, self-help/mutual aid groups embody the 'Five A Day' actions for mental well-being: 'Connect, Be active, Take notice, Keep learning and Give' (Aked *et al.* 2008). Our data support the argument that mental well-being lies not in individual agency, but in a balance between individual and collective responsibility exercised through community networks. Within a wider strategy for social justice, the groups' tailored responses to diverse health and social conditions could make an important contribution to mental well-being for all.

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