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Coronary Heart Disease (CHD) Support Groups: their role and value from the perspectives of members and facilitators

Susan Gregory
Lisa Hanna
Brian McKinstry

(Published September 2007)
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Disclaimer

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EXECUTIVE SUMMARY

Background and Methods:
CHD Support Groups offer long term help to replace or complement help given by health practitioners, families or friends, by providing a location in which lifestyle change can be developed and experiences shared. This study used a number of different research methods to capture how well and effectively these groups operate and how they are viewed by the members and the people who facilitate the groups. The study was undertaken with members and facilitators from seven CHD Support Groups across Scotland. The groups were exercise-based or socially-based, and were selected to reflect location and size. Focus groups with members, observation of group meetings, and interviews with group members and ‘facilitators’ were conducted (sometimes including carers or family members) and analysis of documentary material was carried out.

Findings:
The main findings suggest that membership of these groups was seen as valuable and enjoyable for both exercise-based and social support forms of group. Membership benefits can be seen to fall into three main categories (which are not all mutually exclusive):

1) **Health benefits.** These included: health promotion/illness prevention; accessing/providing information (health and non-health related); facilitating exercise; monitoring each other and a sense of belonging.

2) **Social benefits.** These included: meeting people/reducing isolation; contact with others with heart disease; enjoyment and fun.

3) **Health professionals’ involvement.** This was also a significant factor in how members used, viewed and enjoyed taking part in group activities. This was particularly so in the exercise groups, in which most of this involvement was found.

Problems with the groups tended to be associated with: group dynamics (minor); access and venue issues; and, most significantly, recruitment of new members and linked falling numbers. This last was of particular important to the socially-based groups, some of which sometimes struggled to find a variety of activities for group meetings that were relevant, meaningful and beneficial to members’ cardiac and general health. A lack of new members was often seen as a failing of the medical professions in informing people of the groups’ existence.

Conclusions:
There were three areas that deserve specific comment:

1) **The value of the groups:** Participants enjoyed attending Support Group meetings and felt they had relevant health benefits, whether exercise or non-exercise and regardless of size. The reasons ranged from the view that regular exercise had a positive health impact, to the more nebulous notion of fun and camaraderie that encouraged people into good health. Whilst participants wanted to meet up with people ‘in the same boat’, this was to help ‘moving on’ and leave behind the fears of future illness. Group cohesion provided company, prevented isolation (particularly for people living alone) and promoted an on-going informal nurturing.
2) Medical/health professions: Health practitioners helped to sustain and legitimise CHD Support Groups, and members spoke favourably of monitoring, access to information, and informal expertise and services. The practitioner facilitators encouraged enthusiastic participation to sustain on-going retention. This active participation by practitioner facilitators also provided a form of legitimisation of the group, evidenced by the frustration expressed by members of groups where this kind of input had been withdrawn. Medical and health professionals were also strategic in referral (or non-referral) of people to Support Groups.

3) Exercise versus non-exercise Support Groups: Where exercise had been central to the group’s activities this was seen as a major criterion for ‘success’ by both members and facilitators, and some members of the non-exercise groups expressed an interest in the introduction of an exercise component into their group’s programme. The value of exercise went beyond the effect on physical health, with regular exercise seen as contradicting stereotypes of and fears about heart disease, and reassured members of their capabilities. However, the reassurance from knowing that the exercise was overlooked by practitioners (where they were present) was also of significance, as was an exercise regime that took account of the individual’s capability. There were potential problems over different levels of ability (particularly possible in larger groups) which could have been alienating for people with lesser capability, in older age groups and/or with co-morbidity or who were just more frail.

Recommendations:
CHD Support Groups, whilst providing a valuable resource for people in Phase IV of Cardiac Rehabilitation 3, are variable in form and function, under-utilised by practitioners (possibly due to an uncertainty about their capability) and would benefit from guidance in terms of future potential activities that they might offer to people with heart disease. The Chest Heart and Stroke Scotland Annual Report 2004 focused mainly on services to stroke support (and heart failure) with mention of CHD subsumed within stroke support. There are significant overlaps in the needs of people with stroke and people with heart disease (such as the need for support in making choices and changes to improve future health and prevent the recurrence of illness) that might be utilised into the development of a new framework for CHD affiliated Support Groups. In doing so, there are two areas that might be formally addressed:

Membership aims and activities:
Concerns about the content of the group meetings and about falling numbers suggests an opportunity for the development of an overall strategy for the future of CHD Support Groups. The groups rely largely upon referral from hospitals, cardiac rehabilitation programmes or, less so, general practice, but this is variable and most successful when the links between the hospital and the group are strongest. It is likely that people leave the group when they no longer need support for lifestyle change, but there may also be people who become more ill and feel unable to continue (especially in exercise based groups). It is also possible that members remain part of the group beyond the point at which it is of identifiable value to them.
Membership size and recruitment:
Groups more successful in recruiting may find increased size brings organisational problems. Increases in activity will be subject to venue availability, but, more importantly, reliant on health professionals who give up much of their personal time to run and promote the group(s). In contrast, groups that had falling numbers (including some exercise groups) largely due to a lack of new members, will mean an increasingly ageing membership.

There is considerable potential to develop a strategy that would provide support for people at all levels of capability to promote healthy living. Nevertheless, this would benefit from clear guidelines that, amongst other things, address the process of joining, remaining in and, where appropriate, leaving the group.

Recommendation points:
- Chest Heart and Stroke Scotland should develop a set of baseline aims and objectives as supported targets for their CHD Support Groups, to include: appropriate activities; membership needs to be met; minimum requirements for venue and facilities; entry and exit strategies where necessary.
- Chest Heart and Stroke Scotland should develop a strategy for accommodating the needs of differing members’ characteristics (age; gender; (dis)abilities)
- Chest Heart and Stroke Scotland should facilitate liaison between Support Groups and referral sources (GP practices; CR programmes; Hospital CCUs) to identify what the minimum expectations of the latter would be acceptable to the aims of the former, as encompassed in (1) above.
- Chest Heart and Stroke Scotland should examine the potential for regular (not necessarily frequent) funded input from health practitioners.

It was not part of the remit of this study to identify appropriate Support Group models, but the notion of self help inherent in the ethos of these groups suggests this could be an opportunity to utilise members of these groups in the development of a Support Group strategy (in terms of content, format and aims) that would more effectively provide for their needs.

This study was commissioned by Chest, Heart & Stroke Scotland and carried out at the Research Unit in Health, Behaviour and Change of the University of Edinburgh, between December 2004 and November 2005.
Coronary Heart Disease (CHD) Support Groups: their role and value from the perspectives of members and facilitators

BACKGROUND

CHD health promotion activities provide advice for patients to make individual changes (mainly lifestyle) aimed at preventing further symptoms. However, once in the social context, with its competing needs and priorities, this can be difficult to achieve 1, 2. In Scotland, one form of help with this is the CHD Support Group. As well as health-related support (exercise, dietary, advice etc) some offer broader information (e.g. benefit advice) and emotional help. This structured self-help in a group can complement public policy on health and cardiac rehabilitation (CR) programmes. The CR SIGN Guideline 3 recommends that self-help groups be encouraged. Support Groups form part of new CHD initiatives (such as Managed Clinical Networks) to build on existing models. However, little has been known about how these groups operate and, more importantly, what aspects of the groups’ activities and organisation appeal most to participants and why, warranting formal research. It should be noted that only a small proportion of people with heart disease attend these groups, so this study provides just one perspective on their use and value, that of the people who continue to use them.

AIMS

The overall aim of this study was to examine views and experiences of facilitators1 and members of CHD Support Groups in Scotland. Particular attention was paid to how the information, advice and mutual support members received, as well as any activities and skills that they might develop, were seen to help the management of the consequences of CHD. This study, therefore, aimed to provide information on how Support Groups might: provide long term consistency of healthy living; enhance the potential for self motivation and empowerment; offer a ‘one-stop’ resource for accessing disparate information; and demonstrate the value of self-help for limited public resources.

METHODS

The study used a mixed-method approach. An initial screening questionnaire to Support Group members collected their demographic and medical characteristics and identified those prepared to take part in the study. In-depth qualitative interviews, focus groups and observation of group meetings allowed the flexible exploration of meanings and values and to respond to any sensitive and unexpected issues that arose so that participants could follow at their own pace and in their own language, to record data accurate to their views and experiences. Thus this qualitative approach provided detailed, complex information complementary to the simplified, population based information such as a large scale survey might offer 4, 5, 6. All interviews and focus group discussions were audiotaped, transcribed and checked for accuracy, and comprehensive field-notes made for background detail. Analysis was aided by analysis

1 The term ‘facilitator’ is used here to include both people with heart disease who head up group organising committees, and health professionals who have set up or co-ordinate the groups
software, NVIVO 1.3, to help systematic organization to identify significant themes and highlight issues of importance to the participants.

Advisory group
An advisory group was established drawing membership from interested organisations to offer expertise with strategic aspects of the study and feedback on findings as the study progressed.

Ethical aspects of the study
COREC and British Sociological Association guidelines for ethical research and data protection legislation were adhered to throughout the project.

Selection of CHD Support Groups
Contact details of the groups, their facilitators or chairpersons were obtained from Chest, Heart and Stroke Scotland databases. Telephone contact was followed by an information sheet, explaining the study and participation, being sent to the chairperson and committee of each group. Seven Support Groups, (four exercise and five non-exercise based) were identified, located in Central and Southern Scotland. Selection criteria included socio-economic and geographic characteristics, membership size, family involvement. Initially six groups were approached to participate. Difficulties in recruiting participants from the two small non-exercise groups led us to recruit a further non-exercise group to fulfill the recruitment target set out in our research design.

Support Group characteristics
The seven groups represented a wide range of group characteristics. Two were based in cities, three in medium-sized towns and two in smaller villages. Groups varied in the length of time since their formation from about 1 to 15 years and in membership size from just a few to more than 200 active members. All had a committee, a constitution and an Annual General Meeting although there was variability in the formality of these structures and processes. Of the exercise-based groups, one met weekly, one had one main and one subsidiary class each week and one convened several exercise classes in different locations each week. Of the non-exercise based groups, two met once a fortnight and two met monthly. Overall, most group meetings lasted between one and two hours. Meeting times also varied; several took place in the mid- or late evening; others during the day. Group activities also varied; of the three exercise groups studied, two were member-led, and the third facilitated by staff from the local hospital. All involved a warm-up, some aerobic exercise, games, circuit or personalized exercises using equipment, and a cool-down period. Non-exercise groups also varied in the range of their activities. Two regularly invited speakers to give talks on health and other topics. Two groups had a less regular speaker programme, but spent their time chatting, taking part in other activities (such as quizzes) or listening to information provided by the facilitator. All groups but one organized additional social events, such as short walks and organized visits.

Facilitators’ interviews
In-depth face-to-face interviews were carried out with the groups’ ‘facilitators’. These aimed at eliciting an overview of the history, structure and characteristics of groups and produced a context and information to guide subsequent stages. Eleven facilitators took part in seven interviews, as three groups provided more than one facilitator for the
interview. The facilitator was most commonly the chairperson, but also included other committee members, a physiotherapist and a cardiac rehabilitation nurse.

**Documentary materials**
Several groups offered documentary materials concerning their group (e.g., publicity material, group constitutions, committee meeting agendas, minutes and activities) which contributed to the understanding of group organization, structure, and form.

**Screening questionnaire**
The screening questionnaire together with consent forms, were returned by the respondent in pre-paid envelopes. Subsequent phases of data collection were carried out with people drawn from this screening questionnaire, according to gender, age, and length of membership criteria.

**Screening questionnaire characteristics – summary**
220 group members returned their questionnaires and, overall, there were more male than female respondents (64.5% and 35.5%), but total group membership numbers were not available. Most of the questionnaire respondents were willing to take part in the study (approximately 80%). The age range of group members (8-85 years) was wide because some groups included family members who did not have heart disease (including the 8-year-old son of a member) and who attended regularly. Socio-economic status overall was broadly equal across the groups (categorized by the Scottish Index of Multiple Deprivation Scores), although only a minority of respondents fell within the lowest socio-economic group. A question asking about overall health over the last 12 months found that the majority of respondents considered their health to be either good or fairly good.

A wide range of cardiac conditions were reported with approximately half having had at least one heart attack, and half having had cardiac surgery (most commonly bypass surgery). A much higher percentage of men than women reported most of the types of heart disease (i.e., M.I., hypertension, angina, heart murmur, abnormal heart rhythm) Most respondents lived with other people, usually a spouse or partner but also children. More women than men lived alone. Only one respondent was from a non-white minority ethnic group. The length of time these respondents said they had been members of groups varied considerably (from 1 month to 15 years)

**Observation of meetings**
Participant observations identified the range of group activities taking place, their content, pace, and direction, the varying locations, venues, and facilities, and how people behaved together in different kinds of groups. Field notes were routinely recorded.

**Focus groups**
Focus group discussions were carried out with four of the seven Support Groups. Selection aimed at maximum variation in: gender, age range in the groups, cardiac histories, socio-economic backgrounds, length of membership and living circumstances. Focus groups could not be organised with the groups that had very low membership combined with a low response to our invitation to take part.
Members’ interviews
Most interview participants were aged in their early to mid-sixties. They were selected to represent a range of lengths of attendance at the group to ensure a variety of experiences (average attendance was 5 years). Twenty-seven in-depth qualitative interviews were carried out with thirty participants. The aim was to interview two men and two women from each group, but in one group no women volunteered to take part. Five interviews were paired interviews with a member and their spouse or carer, three of which were also group members. The interviews allowed a follow up to themes that had come up in previous stages and gave people a chance to talk about issues that they might not have wanted to discuss in a group.

FINDINGS

Overall views of participants
Overall, most Support Group members spoke positively about attending the Support Groups and found it enjoyable and welcoming. They were rarely critical of group activities and did not suggest dramatic changes or improvements. Many said they would strongly recommend that others with heart disease join the group, and intended to continue attending the group (sometimes saying that they would keep going until they were dead or unable to walk).

Oh definitely, definitely til I’m crippled and I canny go, that would be the only reason that… No, I would never stop. [Group B, exercise group]

At times, I mean you know especially coming home and it’s a miserable night and it’s raining and I’m “What am I doing coming away oot here?” And my wife’ll say “Are you no’ going back?” “No, I’m no going back”. And the next fortnight I’m away again.
[Group E, non-exercise]

The few negative comments were from people who continued to attend their Support Group and often went on to speak more positively about the group and its role. Some frustration was due to the withdrawal of external support (see later).

A detailed analysis of the views and experiences expressed by the participants in this study suggests that the findings fall into four main areas (although these are not necessarily mutually exclusive):

Health Benefits
Group membership was seen to have overall health and wellbeing benefits, but also that there would have been a deterioration of health had they not been group members. They felt that group activities raised individuals’ spirits, supplied stimulation, and so was seen as giving both health and social benefits. A reduction of a sense of isolation was very important, by: providing activities and ‘something to do’ for participants; allowing contact with other people who had heart disease; also meeting people in general and accessing company; and the development of a sense of community, often accompanied by a reassuring monitoring of each others health and well-being. Attendance often
provided information on cardiac health and other matters of interest to members. In the exercise groups, the facilitation of exercise activities was seen as central.

I mean I had three years before I… from my first heart attack to when I joined the… well when the [name of group] club started, the [name of group] started and I felt those three years I was going down. Now I feel it’s at least stabilised now. [Group C exercise group]

Health promotion/illness prevention
The majority of groups had a strong ethos that they were there to assist their members of ‘moving on’ to lead a full, active and ‘normal’ life without undue emphasis on heart disease or taking on an illness identity that could restrict a return to ‘normal’ functioning. Many vehemently denied dwelling on any health problems; nevertheless, most members said that there were always people at the group that they could talk to if they had a particular concern. (In fact, the person to confide in about health matters was often seen as the health professionals (where there were these) or the committee members):

[After a previous time limited hospital-led course], that’s it, I’m left on my own. That’s the one thing cardiac patients don’t want, they want this little bit of reassurance that these people give us, ….. you know, and even just getting together helps… talking with one another makes all the difference. [Group D, non-exercise group]

And I’ve found the group a lotta help… and obviously it’s helped other people… if it wasn’t for the heart group basically I would be in my box. [Group E, non-exercise group]

Information (health and non-health related)
On the whole, it was the cardiac rehabilitation class that members had participated in prior to joining the Support Group that was reported as the main source of lifestyle advice (such as diet, smoking etc). Nevertheless, the groups did act as an additional conduit for information. Non-exercise based groups had more time for the dissemination of information to members as their meetings were not occupied with exercise. Visiting speakers were also more likely to be invited to the non-exercise groups, to form part of the group activities, although not all social (non-exercise) groups had regular speakers. Two of the four non-exercise based groups that took part in the study arranged speakers to give a talk at most meetings. In contrast, some of the exercise-based groups occasionally invited a speaker to attend their regular meeting or on special occasions such as for an Annual General Meeting. Elderly members, who might not otherwise know where to access information, found this particularly useful. Talks by pharmacists were seen as particularly helpful, and, in fact, it was not unusual (across groups) to hear participants speak of confusion and a lack of awareness about the medication and wanting to clarify this. However, talks were not necessarily always about health, illness or heart disease, and other non health-related topics also formed part of some Support Groups activities. Anything that was identified as interesting, stimulating and/or contributed to the sense of group cohesion might be included, with some of more practical relevance, such as providing benefits advice.
Information came from a range of sources:

(a) from facilitators:

*Sometimes they want...if there’s anything that we can pass on to them. I mean I’m always cutting pieces out of the paper and I say “Of course, you’ll realise now the full doc doesn’t operate anymore, that was the emergency service” I says “You’ve got to phone this number” They all want to take it down. That’s something they didn’t bother to read in their local paper. And you keep them advised of these things.* [Group D, non-exercise group facilitator]

*But if there’s anything new crops up [medication information] …they’ll post it on the noticeboard.* [Group C, exercise group]

(b) from speakers:

*We’ve had a cardiologist, one of the two from [name of town] came along one evening. We had, he’s now retired, a cardiac surgeon from [name of hospital] and his talk was very interesting.* [Group G, non-exercise group]

*The most important thing I found was, the best person I’ve listened to in the whole year that we had of all these speakers, was the pharmacist, that was able to take down, for the whole crowd, “What do you take?” and she wrote them down on the blackboard and she explained every one of them, that was important.* [Group D non-exercise group]

(c) from literature:

*Chest, Heart and Stroke or the British Heart Foundation literature was sometimes displayed and made available for members:*

*I mean we can give them literature that we get from the Chest, Heart and Stroke... and the leaflets are very good, they’re very well laid out and they’re in layman’s terms, you know.* [Group E, non-exercise group facilitator]

**Exercise**

Promoting regular exercise, where appropriate, in people with heart disease has been a central theme of health promotion messages, especially at cardiac rehabilitation classes. The exercise groups we studied varied in the type, pace and range of exercise they offered. Two of the groups were quite competitive, one involving competitive sports (such as volleyball and badminton), whilst the other included team games that involved physical exercise. The remaining exercise group had members who were concerned about the boisterousness of such games, and so limited their activities to aerobic and other largely non-competitive games. Nevertheless these findings suggest that this is an effective location in which to encourage this kind of activity, both in the exercise and non exercise groups. In those groups that had exercise as the central activity, three themes could identified:
(a) motivation:

Whilst many participants felt they were physically active through a range of other activities, others commented that they probably wouldn’t take exercise by themselves.

And a lot of people need motivation to exercise. I'm not somebody that likes to… I have to be motivated and I know that, I recognise that for myself. And this club motivates me. [Group B, exercise group]

Well you can see people, twenty, thirty, forty years older than you managing, you know, to do certain things, it definitely gives you a big boost. You think “Well if that person that can hardly walk…” you know, “If they can do… get up there and do their exercises then I'm damn sure I can get up there and do my exercises”. [Group C, exercise group]

(b) moderation:

All exercise-based groups stressed moderate rather than excessive exertion as the goal, and an individualized approach allowing members to exercise at their own pace. This moderate approach was reassuring to participants, but also contradicted the stereotype of a restricted life with heart disease.

Participant 1: Can I just reinforce it all… reinforce that building your confidence is a sure side of it as well. Em, I didn’t have a heart attack, I had surgery, I had a valve replacement and after my six week check-up at the hospital, they told me about the class. And, at first, I was terrified that I wouldn’t be able to do the processes in the class. But, you know, after the first day, you realise that… everything at your own pace. (laughter)
Participant 2: That’s the motto.
Participant 3: Mmm, true.
Participant 1: And just being able to improve your confidence and realise what you are able to do and also have the chance to talk to other people who’ve been through the same thing was a big… a big help. [Group C, exercise group]

(c) enjoyment:

All exercise group participants spoke of enjoying the exercises and, as well as feeling that the exercise had a beneficial effect on their health, the combination of exercise with fun and banter enhanced the group atmosphere. The non-exercise groups varied in attitudes to exercise, with some participants favourable towards increasing the exercise available to members beyond activities such as local walks (although some ended in the local pub) and, in one case, association with an over-fifties exercise class. Some spoke of the possibility of encouraging trips further afield for walks, cycling and other outdoor pursuits facilitated by the local council. There were, however, mixed feelings about moving to a more exercise oriented group; not all groups spoke positively about introducing exercise as a formal component of their group’s activities and not all members expressed keenness to do so. A number felt they led sufficiently active lives already and so did not require any further exercise. In some cases it was simply that members felt that they or others were too elderly or frail, particularly if they were dealing
with more than one medical condition, and there was also concern that an emphasis on exercise might alienate people unable to take exercise. One participant (from an exercise group) spoke about feeling frustrated at being unable to exercise at the level displayed by others who were, in fact, older in years. Nevertheless, some who had been members of exercise groups for some years, spoke of a commitment that would motivate ongoing attendance despite any inability to exercise:

*I'm no' able to walk very far, I've got my walking stick. I've got one of the wee three wheeler things, you know. But eh, I still go to the [group name] every Wednesday.* [Group C, exercise group]

**Belonging and monitoring**

An overlap between a health and a social benefit could be found in a sense of camaraderie that was very evident (especially during the observation sessions) in many of the Support Groups. A number of the groups conveyed a strong sense of group identity and community-spirit that was clearly a social benefit. However, the way in which some spoke of belonging to a caring and nurturing group that included monitoring each other’s health and well-being can also be seen to embody a health benefit as well. For example, if a member mentioned feeling under the weather or just missed a meeting, this would be followed up by a phone call or visit.

*It's like a big happy family...everybody is concerned about everybody else when they're not well. The first thing is that if somebody goes and they're no' there and everybody'll say “Where's so and so?” you know.* [Group A, exercise group]

*As I mentioned, this sort of cohesiveness of the group built up, I think that's very important. And that is equally as important as the rest, because that establishes the self-help bit of the process...I think the most important thing is a sense of belonging. If people feel they're part of the group, they're willing to come along. If they come along, the thing thrives.* [Group D, non-exercise group facilitator]

*...I do think that the Support Group is good. If nothing else, we've...we helped that chap [an anxious member] that I was saying...you know, we helped him. And I suppose we help each other in a way without realising it.* [Group E, non-exercise group facilitator]

**Social Benefits**

Participants identified group attendance as a valuable source of activity for people with CHD, many of whom were retired due to age or ill-health. Keeping socially and physically active was identified as extremely important in regaining and maintaining good health in chronic disease and after a CHD-related event or diagnosis. Participants often spoke about the necessity to avoid isolation or to ‘get into a rut’.

**Meeting people/reducing isolation**

Many participants spoke of the Support Group providing a focus and something to do rather than staying at home. Meeting up with people regularly, including new people, was of great value to the members, who said that, amongst other things, it reduced a sense of isolation. Even where people did not see each other outside the group, the
companionship in the weekly or monthly meetings was immensely valuable. This was especially the case for members living alone and far from immediate family. Isolation was seen as particularly detrimental to health and well-being:

*Exercise is good for you, we know that, but it's the company more than anything else.* [Group A, exercise group]

*[if I didn’t go to the group] I’d just be on my own. I mean my friends are quite understanding, but you’re not with your friends all the time… it would be very easy for someone like me to become isolated. I think that’s probably the reason why I go.* [Group D, non-exercise group]

**Contact with others with CHD**

Again, the overlap between the health and the social in terms of benefit can be seen here. The notion of monitoring was not always exclusively intended for the benefit of others. Most participants said it was important to be able to meet others ‘in the same boat’ because this helped them by, firstly, reassuring them that they were not alone, which was comforting:

*Aye, it’s a boost, you know, ‘cause, as I say, you’re all there wi’ the same sort of problems and you can see everybody else enjoying theirs’ an’ you’re enjoying yours’l as well, you know, so it shows you that there is mair to life after a heart attack, your life does go on.* [Group A, exercise group]

Second, seeing others with more debilitating heart disease indicated there were ‘others worse off than themselves’. This was particularly so if they could see these people progress and improve. It gave them confidence in the potential for their own recovery and so helped to develop a positive attitude about their long-term health:

*But then again, when you go to this [name of] group and you meet people that’s went through the same as you and they’ve been there maybe a couple of year before you and you look at them an say “Well they look healthy, they look alright”. And then you begin to build up your… you get confidence, meeting people the same as yours’l*. [Group B, exercise group]

*I hate to say it this way, I mean it’s a bit cruel, but it was nice to see someone that had been worse than you and survived…It was nice to see how they were getting on and stop me sitting moping and saying… in the corner “I’ve had a heart attack, I can’t do anything”’. You can do anything within reason.* [Group F, non-exercise groups]

**Enjoyment and fun**

On the whole, there was much laughter and banter at group meetings and among members and facilitators. For many, the specific group activities (as mentioned above, in particular exercise but also activities and trips arranged outwith normal group meetings) were enjoyable, but also the sense of fun and laughter they found when spending time regularly with each other was a strongly cohesive force and motivated regular attendance. Participants spoke of a friendly atmosphere having a mood-boosting effect, and this was the case for both exercise and non-exercise groups:
If I had to say there was one thing more than anything else that kind of helps keep things going, it’s a sense of fun. Because, unless folk actually like what they’re actually doing, they’re not going to keep on doing it. And very definitely throughout everything really is that kind of sense of fun, I think that’s really important. [Group C, exercise group facilitator]

I think, as much as anything, the people in the [name of group] enjoy the social side of the meetings as well. It’s not just... just totally medical advice, you know, it’s much broader than that. It’s a friendly, chatty group and sometimes you’ve to pull them off their blethering in order to get onto the subject that you want to, which is very good really, because it means that the group has gelled. [Group D, non-exercise group facilitator]

Health Professionals’ Involvement

Health professional involvement in the group varied substantially, but was seen as a key facilitatory factor in groups in which they were, or had been, heavily involved, and a cohesive force strongly contributing to group success. This involvement (usually cardiac rehabilitation nurses but also physiotherapists) was sometimes in a voluntary capacity.

These practitioners were seen as fulfilling a number of important roles:

a) They were a highly-valued source of medical knowledge and reassurance. For example, in exercise classes, the health professional presence reduced concerns about precipitating a fatal event.

b) They sometimes provided monitoring of health indices, by checking weight and blood pressure regularly, which reassured members that their condition was being actively managed by an expert.

c) They were also seen as a source of information about worries members might have about their cardiac health, (including medication) and so provided a readily accessible source of information or clarification. These what might be described as “informal consultations” were seen as a way of avoiding long waiting times and lack of personalised care that they had found in GP or hospital systems and sometimes as a means of ‘fast-tracking’ patients into the formal health care system if necessary.

Health practitioner involvement was highly prized by group members. In fact, where the relationship could be seen as the strongest and most involved, the group as a whole appeared to thrive particularly well:

After my first heart attack, you know, the GP says “Take exercise”. Again, I was finding there, while taking exercise, getting severe angina pain and there was a fear about it. But after the classes, you knew that the medical attention was there, if anything went wrong. And it gave you confidence to push yourself that bit further than you probably would normally do. [Group C, exercise group]
There were also strong links between the perceived commitment by health professionals and a cohesive and robust group identity, and many participants actively attributed the success of the group to the practitioner involvement:

But, oh, it’s just… we have got… the following that we’ve got and the club that we’ve got and we do what we do because of the two [health practitioners] who lead it because they instill so much confidence and make people want to do… and make you want to come back, you know, it’s wonderful, it’s a wonderful, wonderful club. [Group C, exercise group]

Some groups (particularly exercise based groups) mentioned support from external organizations, such as a hospital, a cardiac rehabilitation programme, a community education programme or a healthy living centre, and these were sources of referral to the group. These links could be seen as strongly ‘legitimising’ the group’s existence, purpose, role and identity. Some groups had member representation on local managed clinical networks, guidelines boards or health councils; others had lobbied extensively for increased cardiac services in their region. Some groups felt that this relationship was strong and mutually respectful, but others felt ignored or undervalued by health services:

We find that the groups are very small and it’s due to the fact that the hospitals do not have an involvement. The hospitals do not refer patients to the groups…I think hospitals could be more co-operative. [Group E, non-exercise group]

Where formal health professional involvement had been reduced, or where practitioners who had been involved voluntarily had been unable to continue, group members spoke of their frustration and dissatisfaction. For example in one group, a cardiac rehabilitation nurse had been withdrawn by local services:

[It was] a severe humiliation to the staff that were there, you know, because they were there on a weekly basis and there was, what was it, two times that they were there that somebody actually took ill and they responded quickly and they actually saved the guy. And eh, if that happened again, well who’s answerable, you know? [The group has] come to accept it now because they know it’s on a monthly basis, but to begin with it was quite detrimental, you know. A lot of the folk could’ve actually walked away and no’ bothered coming back because of that. [Group A, exercise group]

Practical Issues

Over and above the views of members about their Support Groups, there were a number of issues that emerged that fall into a category of the practical. These involve (i) the concrete location of the venue and its use, such as cost, access, facilities and permanence, as well as (ii) the concerns that members had about membership numbers, recruitment and referral and what might influence this.

Venue

There were a few practical issues that, whilst not seen as currently a problem for these groups, had the potential for difficulties in the future:
(a) cost:

The issue of the cost of group membership was important only to a minority of participants, although, as these groups either charged a nominal fee or had no fee at all, this is not surprising. In some groups there was resistance to the idea of paying and, in one, an aversion to the possibility of a change in their venue arrangements taking place which would mean that the group would have to cover the venue rental when previously it had been supplied to them at no charge. In other groups, especially the exercise groups, some members said that they were comfortable paying, but willingness to contribute financially could depend on personal financial circumstances; some felt less able to pay due to being unemployed or on benefits.

(b) access:

The majority of group members that took part in this study had their own cars to get to the group venue; others lived close enough to walk or cycle in good weather, and carpooling was often organized with lifts available to members who did not drive or were unable to due to ill-health. Public transport was used by some and the ease of doing so depended on the services in the area which tended to be easier in the larger towns or cities:

*As long as I’m able to drive I would hope to continue attending. Umm, I don’t know that I would go if I had to rely on public transport.* [Group G, non exercise group]

(c) Facilities and permanence:

Some groups reported having to change venues over the course of their existence, although most were reasonably satisfied with their current venue and facilities. There were a range of types of premises used, such as hospital-based rooms or recreation halls, schools, community and leisure centres. Some groups were not charged whilst others paid a modest fee to rent the space available. Having a permanent space dedicated to the group was something that was highly valued by those groups who had it and sought after by others. One group wished to build their own dedicated venue due to the high success of the group’s fundraising activities, although there were doubts about how this might work, because of local NHS changes. A lack of permanency or facilities is bound to have an impact upon the way the group is viewed by both members and potential members, as illustrated by experiences of these two groups. One group, which used two venues on alternate weeks, expressed a preference for the well-equipped local gym they were able to use over the limited equipment available at their alternative venue. Another group was evicted from their venue throughout the summer months when the space could be rented out at a much higher cost than they were able to pay:

*The only thing is… that we do miss, is the apparatus at [venue], because it’s in a little tiny room, you couldn’t… mean you couldn’t even use it and most of its broken.* [Group B, exercise group]
As I say, in the summer when they turf us out to let the [other] people in, we just wander about somewhere, .... probably....finish up in a pub. [Group E, non exercise group]

Membership

(a) falling numbers:

Concern about membership tended to be expressed in terms of falling numbers rather than rising numbers and the issue of dwindling membership and difficulty in recruiting new members was a highly salient issue for group members:

When I was secretary I just… I just made it my mission I think, to try to get people to come. And when they were dropping off, it was so demoralising, you know. [Group B, exercise group]

I mean I think we function reasonably well, as a group, other than the fact that we fail to attract very many new people, you know. [Group E, non-exercise group]

Reasons for falling attendance was given as members dying or becoming too ill, or a reluctance to attend during winter evenings, especially if there was poor public transport, or was speculated as people having alternative exercise arrangements or, possibly, being in denial of a cardiac condition.

(b) referral:

A lack of referrals and support was a major reason given for the problem of recruiting new members and many members expressed considerable disappointment at the lack of support from practitioners (such as GPs or cardiac rehabilitation services) who they felt should be able to do this – this was largely a problem faced by non-exercise groups. In contrast, there were groups, most notably one of the exercise-based groups with strong links to local coronary care services, who had an extremely large and active membership and indeed on occasion had difficulty accommodating their members within the limited space available. Across groups, a larger group size was generally seen as positive and something that would improve the group:

The bigger the club is, the better its gonny be ’cause you’re always gonny have somebody wi’ suggestions, know what I mean, something better, ken suggestions. [Group B, exercise group]

Really, it is good, I enjoy it, I really dae enjoy it but, as I say, it’s beginning to get boring because there’s no enough goes on. [Group F, non-exercise group]

(c) age and gender:

Although the age range of the membership of the groups studied was quite wide, the majority of members were over retirement age, which could attract some problems. For older members, trying to keep up with younger and/or fitter members in exercise groups could be daunting, especially in the early stages. In contrast, younger people with heart
disease could find being surrounded by people considerable older than them disconcerting.

But I found it very difficult to join in because they’re all a lot older than what I am. And I found it very hard but I kept going. [Group E, non-exercise group]

In contrast, the gender balance in the groups rarely came up as an issue for members of these groups and of all participants, only one female participant said that she preferred attending the group when there were other women present. However, it is, of course, possible that those potential members who were likely to be affected by a gender imbalance may have chosen not to join the group.

CONCLUSIONS

This study brings together the views and perspectives of people with heart disease who are members of seven CHD Support Groups from selected locations in Scotland. The groups were chosen to reflect (within the constraints of the size of the study) the main characteristics likely to be found in CHD Support Groups generally, for example gender, location (urban/rural) exercise/non-exercise, size and length of attendance, age, family involvement etc. Whilst the data collected indicates a wealth of information and potential for interpretation about the use and value of these groups (which will be pursued in future publications), there are three areas that deserve specific comment in terms of conclusions:

1) The value of the groups:

The overwhelming message from the people who took part in this study was that they enjoyed going to Support Group meetings regularly and felt a benefit that was relevant to their health. This was expressed by virtually all participants from all of the groups, whether exercise or non-exercise and regardless of membership numbers of the group. The reasons for this viewpoint ranged from the more concrete expression that regular exercise had a positive impact on physical health, to the more nebulous notion of fun and camaraderie as a means to support, monitor and encourage people into good health. In this sense good health can be seen to incorporate psychological wellbeing into cardiac health. This draws attention to the tension that takes place, during the course of recovery from a heart incident, between the need to return to a ‘normal’ life, and the need to follow healthy living advice offered to people with heart disease. Thus, whilst participants mentioned how useful it might be to meet up with people ‘in the same boat’, this was often to do with finding ways that would promote ‘moving on’ (in a way that might be described as moving from being seen as a patient to being seen as a person) and leaving behind the fears and worries generated by the cardiac event. This group cohesion was said to provide company and ‘things to do’ (both within the group meetings and at organised social events); prevent isolation (particularly for people living alone) and promote an on-going nurturing that involved caring and noticing when people were below par or absent from the group.
2) Medical/health professions:

Another important message from this study has been the place and role of practitioners of different kinds in sustaining and legitimising CHD Support Groups. Firstly, for those groups that had currently, or had had in the past, a major input from practitioners, the value attached to this role was very clear. Members spoke of a monitoring from and access to information, expertise and services that could be assumed from these practitioners in an informal way that nevertheless had become a trusting personal relationship. Practitioner facilitators made it clear that this was something that they encouraged as a means by which enthusiastic participation and on-going retention could be sustained. Secondly, it also seemed clear from members and practitioner facilitators that the active participation of these professions provided a form of legitimisation for the group as a formal and valid organisation. This was endorsed by what could be seen as a level of frustration or dissatisfaction expressed by members of groups where this kind of input had been withdrawn and indicates a place taken by professions in establishing the credibility of a group. Thirdly, and linked to this last, is the role played by the medical and health professionals generally through referral (or non-referral) of people with heart disease to Support Groups, an issue raised several times by groups where numbers were falling (both exercise and non-exercise) and the future of the group was uncertain.

3) Exercise versus non-exercise Support Groups:

It is tempting to assume that those groups that place exercise as a central feature of the group’s activities have captured a major criterion for ‘success’, whether in terms of members’ views or healthy outcomes generally. It is certainly the case that for those groups that had exercise as the pivot for and main content of their regular meetings, this was seen as a measure of success by both members and facilitators, particularly so in group C. It was also the case that some members of the non-exercise groups expressed an interest in the introduction of an exercise component into their group’s programme. The reasons given for the positive value of exercise was not limited to the effect on physical health, in that involvement in regular exercise was seen to contradict stereotypes of and fears about heart disease, and many saw this regular group activity as both reassuring members of their capabilities and encouraging a supportive atmosphere between members. There were also positive by-products of this activity, such as walking groups and some social events. Nevertheless, participation in these exercise activities could be seen as being tempered by a caution born out of having had a cardiac event. As mentioned earlier, members expressed a reassurance that came from knowing that the exercise was overlooked by practitioners – people with the expertise to deal with any event that might arise, (although not all exercise groups had a health practitioner involved). They were also supportive of an exercise regime conducted in a forum that allowed an individual approach to the activity (i.e. taking account of an individual’s capability). Linked to this are the potential problems where there were likely to be different levels of ability (particularly possible in larger groups) which could alienate people with lesser capability, in older age groups and/or with co-morbidity or are just more frail.

Finally, although criticisms were less likely to be expressed and seemed less evident, there were a few negative comments made by some members. These, apart from
concerns mentioned earlier about problems associated with exercise in groups, largely reflect criticisms likely to be made of groups generally, rather than groups specifically related to heart disease, or even any kind of chronic illness. A lack of formal structure, autocratic organisers, cliquishness or lack of a friendly or welcoming atmosphere, internal tensions related to personalities, or content of the meetings were sometimes mentioned, but this seemed unlikely to trigger leaving the group, coming as they did from people who (often) had remained members for many years.

Nevertheless, it is clear that these CHD Support Groups, whilst providing a valuable resource for people in Phase IV of cardiac rehabilitation, are variable in form and function and under-utilised by practitioners. Anecdotal evidence from some medical/health professionals has suggested that in some areas there is a reluctance to refer CHD patients to Support Groups in the absence of clear indicators of the value they offer, from a public health point of view. For such groups to flourish they would benefit from guidance on a range of matters, but certainly in relation to the potential for activities that are clearly health related, that they might offer to people with heart disease.

**POLICY IMPLICATIONS**

Public policy across the UK but particularly in Scotland has recognised the importance of addressing public health in the 21st century at both primary and secondary level, and acknowledges that CHD needs to be high on the list of areas that remain of concern.

For example:

1) *Towards a Healthier Scotland* (1999) promised a major prevention initiative aimed at coronary heart disease to be undertaken at Life Circumstances, Lifestyles and Prevention levels. In doing so, this document highlighted a move towards greater connections between aspects of life that are directly and indirectly linked to and have an impact on health by creating partnerships between those agencies most concerned with health: the Scottish Office, NHS Health Scotland, the Health Boards, COSLA, local councils, the voluntary sector, the media and so on. Using the analogy of ‘a jigsaw’, it stressed the need for joined up action assuming a value added outcome for any action that is part of a coherent programme. Health information for the public generally was seen as an important part of this strategy and acknowledged the current and potential role played by Support Groups in this task (p41):

*Comment: What is not mentioned is the potential for such groups to go beyond conveying information to actively encouraging healthy living.*

2) *Our National Health: a Plan for Action, a Plan for Change,* in 2000, produced a range of aims for the Scottish Executive to improve health generally and services for the ill specifically. A need to involve patients and to encourage working in partnership with staff was central to this document, indicating collaboration as an important goal:

*Comment: These points, however, exhibit an assumption that this will be achieved through communication on an individual basis, ignoring the potential for utilising groups for collaborative consulting, action and involvement.*

20
3) The *Coronary Heart Disease and Stroke Strategy for Scotland*, in 2002, focussing specifically on heart health, highlighted new ways of working through Managed Clinical Networks. In addition to providing a conduit through which joined up services could be promoted and managed, this strategy foregrounded the need to ‘put patients’ interests at the heart of service design’ (Malcolm Chisholm, Ministerial Forward to document piii). Whilst workforce increase, training and IT development formed a large part of this document, in fact, *prevention*, at both primary and secondary level, was central:

*Comment: For the purposes of this working paper, the recommendation that MCNs ensure the participation of potentially excluded groups (women, older patients, those from socio-economically deprived areas) into cardiac rehabilitation programmes is of note. Unfortunately, the strategy document fails to note the potential for Support Groups to extend the activities promoted within the (necessarily) time-limited CR programmes over a longer time period, or to reach out to people less likely to take up the CR invitation.*

4) *Improving Health in Scotland: The Challenge*, in 2003, focused largely upon the role of the Scottish Executive and its key partners to ‘help bring about a healthier society’. Interestingly, rather than targeting specific populations or health issues, this challenge was seen, in this document, in terms of four strategic times and/or places in the lifecourse (early years, teenage in transition, the workplace, and communities). For the purposes of this working paper, it is the area of communities that is most relevant. Although the notion of ‘community’ was not clearly set out in the document, and because the document addressed ‘health’ more widely than individual physiological health (or illness), the approach sought to, amongst other things, “encourage, support and enable individuals and communities to take shared responsibility for their own health and to work together to bring about improvements”. Social improvement partnerships (SIPs), healthy living centres (HLVs) and other community based initiatives were expected to be involved, focussing upon a series of special focus programmes, of which a number were directly relevant to lifestyle changes recommended to people with heart disease (physical activity, healthy eating and smoking):

*Comment: Whilst specific communities are not mentioned in this document, it is not difficult to imagine a place for CHD Support Groups to play a part.*

5) *The Expert Patient: A New Approach to Chronic Illness for the 21st Century*, (2001) specifically addressed the initiative set out in the 1999 *White Paper Saving Lives: Our Healthier Nation*. This followed the view that the knowledge and experience of patients was an ‘untapped resource’ that might be utilised to promote the development of lay-led self-management programmes for people with chronic diseases. By doing so this would, amongst other things, develop self confidence, better management of medical conditions and so allow great control and independence to enhance quality of life. Most of the aims of the vision laid out in this document for a successful expert patients’ programme chime with those expected for people recovering from heart disease although CHD is not included in the seven chronic illnesses used to illustrate the document (although diabetes mellitus and heart failure are included and CHD is mentioned at particular points of the document):
Comment: Interestingly the self management programmes recommended seem to pivot around training courses aimed at the individual and individual patient’s negotiation with medical and health professionals, rather than any group negotiation process. Nevertheless, the document acknowledges a vital role played by patient organisations in developing these programmes. Again, the potential for Support Groups to play a part in this process can be anticipated.

RECOMMENDATIONS

Chest Heart and Stroke Scotland, in its Annual Report 2004, focused mainly on services to stroke support (and heart failure) with mention of CHD subsumed within stroke support. These services are developed in consultation with local people and are community services run by volunteers and offering a range of activities – exercise, social and games events, outings, support and friendship. Whilst the issues of relevance to people managing stroke (both patients and carers) may include on-going physical limitations not always of concern to people recovering from M.I., there are significant overlaps, in the need for support in making choices and changes to improve future health and prevent the recurrence of illness, that might be utilised into the development of a new Framework for CHD affiliated Support Groups. In doing so, there are two areas that might be formally addressed:

Membership aims and activities

Whilst CHD Support Groups are clearly seen as providing a useful role by the people who use them, there were the occasional concerns expressed by some members about issues around the content of the group meetings and about falling numbers. This suggested an opportunity for the development of an overall strategy for the future of CHD Support Groups, to which this report could offer a contribution. The study identified noticeable differences in how groups organised and operated, and no real evidence of entry or exit strategies. The groups seemed to rely largely upon referral from hospitals, cardiac rehabilitation programmes or, less so, general practice. This seemed to be very variable and most successful when the links between the hospital and the group are strongest. There was no clear indicator of an optimal time period for membership of these groups, or whether there should be one. It is likely that people chose to leave the group when they feel they have established the lifestyle changes recommended to them and no longer need support for this, but there may also be people who become more ill and are unable to continue (especially in exercise based groups). There was also no clear evidence in the literature or from this study about any alternative sources of long term support (if any) that people with heart disease who do not attend Support Groups might turn. There is the potential within these groups to provide support for people at all levels of capability that would promote healthy living within the physical constraints of the individual. Nevertheless, our view was that it is important to distinguish between membership of groups that improve and promote healthy lifestyles and membership of groups that might promote a ‘sick role’ mentality, and would need to be addressed within a framework for CHS Support Groups.
Membership size and recruitment

Whilst remaining in a group (especially an exercise-based group) might be of value to ensure that following health advice such as diet, exercise and quitting smoking was sustained, we felt this had some inherent potential problems. In groups more successful in recruiting members there could be a critical mass which, once surpassed, might make the reasons for the group’s existence difficult to maintain. Exercise needs space and social support, and mutual monitoring needs numbers small enough to ensure facilitative social interaction. One of the exercise based groups we looked at was particularly successful in recruiting participants, so much so that they had set up more than one weekly meeting and at different times of the day. Clearly this increase in activity can only continue subject to venue availability, but perhaps more importantly, would be reliant upon enthusiastic health professionals who, we discovered, gave up much of their personal time to run and promote the group(s). In contrast, a number of groups we looked at had falling numbers (including some exercise groups) largely due to a lack of new members, which could mean an increasingly ageing membership over time. The issue of the differing needs of different kinds of people (men and women, different ages, employed/ not employed) would need to be addressed within a framework if future membership was to encompass the range of people who might benefit from membership of such a group.

Recommendation points

- Chest Heart and Stroke Scotland should develop a set of baseline aims and objectives as supported targets for their CHD Support Groups, to include: appropriate activities; membership needs to be met; minimum requirements for venue and facilities; entry and exit strategies where necessary.
- Chest Heart and Stroke Scotland should develop a strategy for accommodating the needs of differing members’ characteristics (age; gender; (dis)abilities)
- Chest Heart and Stroke Scotland should facilitate liaison between Support Groups and referral sources (GP practices; CR programmes; Hospital CCUs) to identify what the minimum expectations of the latter would be acceptable to the aims of the former, as encompassed in (1) above
- Chest Heart and Stroke Scotland should examine the potential for regular (not necessarily frequent) funded input from health practitioners.

It was not part of the remit of this study to identify appropriate Support Group models, however, self help and self management could be seen to be fundamental to these groups even if not formally stated, and was one that could be built upon. The notion of self help has been stressed as an important way forward for clinical practice, as mentioned earlier in relation to ‘the expert patient’. This offers the opportunity to utilise members of these groups into the development of the Support Group (in terms of content, format and aims) that would more effectively provide for their needs.

FURTHER RESEARCH

Issues that emerged during the course of this and other studies undertaken by the project team have suggested further research that would more fully elucidate the value
and/or limitations of these groups. Currently further work is being undertaken by the research team to address a number of perspectives:

- A questionnaire study, informed by the findings from the current study, to explore to what extent the findings are applicable to Support Groups across Scotland (funded by Chest Heart and Stroke Scotland and completed in February 2007, Working Paper forthcoming).
- A PhD studentship (Angela Jackson, supervised by Dr. S. Gregory and Dr. B. McKinstry) to investigate the experiences and perspectives of people with CHD who do not use rehabilitation services, including long-term community support/self-help groups (funded by the University of Edinburgh to be completed 2008).

Proposed future work (not yet funded) would examine:

- The perspectives of health and medical practitioners on the role and value of CHD Support Groups
- The perspectives of families and carers of people with heart disease on long term support systems.

Acknowledgements

This study was commissioned by Chest, Heart and Stroke Scotland. We gratefully acknowledge the seven CHD Support Groups who participated in this study, and the group facilitators and members who responded to our screening questionnaire, took part in interviews and discussion groups, and permitted the researcher to participate and observe group meetings. Thanks are also due to members of staff from Chest, Heart and Stroke Scotland who assisted with background information about Support Groups: David Clark, Kathleen Frew, Jennifer Kerr, Fiona Leslie and Louise Peardon, and members of local CHD managed clinical networks in the areas in which participating groups were based (not named to maintain anonymity).

Advisory group membership

The research team would like to thank the members of the project’s advisory group for their input and feedback throughout the project: Dr. Chris Baker, David Clark, Kathleen Frew, Professor Linda McKie, Sarah Perkins, Dr. Douglas Stuart and Diane Yellowlees.
REFERENCES


5. C. Pope, and N. Mays, Qualitative Research: Reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research. BMJ 1995;311:42-45 (1 July)
Appendix 1: quantitative findings from screening questionnaire

**Questionnaire respondent characteristics: gender composition by group:**
220 group members returned their questionnaires in total (numbers of respondents in each group are an approximate reflection of total group members, but exact membership numbers for all groups was not always available).

<table>
<thead>
<tr>
<th>Group</th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>14 (58%)</td>
<td>10 (42%)</td>
<td>24</td>
</tr>
<tr>
<td>B</td>
<td>7 (64%)</td>
<td>4 (36%)</td>
<td>11</td>
</tr>
<tr>
<td>C</td>
<td>101 (66%)</td>
<td>53 (34%)</td>
<td>154</td>
</tr>
<tr>
<td>D</td>
<td>10 (71%)</td>
<td>4 (29%)</td>
<td>14</td>
</tr>
<tr>
<td>E</td>
<td>3 (75%)</td>
<td>1 (25%)</td>
<td>4</td>
</tr>
<tr>
<td>F</td>
<td>2 (100%)</td>
<td>0 (0%)</td>
<td>2</td>
</tr>
<tr>
<td>G</td>
<td>5 (45%)</td>
<td>6 (55%)</td>
<td>11</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>142 (64.5%)</td>
<td>78 (35.5%)</td>
<td>220</td>
</tr>
</tbody>
</table>

**Questionnaire respondent characteristics: age range & gender:**
Questionnaire respondents’ ages ranged from 8 to 85 years (the 8 year old was a family member who regularly attended but did not have heart disease).

<table>
<thead>
<tr>
<th>Age (years)</th>
<th>Minimum</th>
<th>Maximum</th>
<th>Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male (n=142)</td>
<td>8</td>
<td>85</td>
<td>66.7</td>
</tr>
<tr>
<td>Female (n=77)</td>
<td>35</td>
<td>85</td>
<td>66.2</td>
</tr>
<tr>
<td>All</td>
<td>8</td>
<td>85</td>
<td>65.5</td>
</tr>
</tbody>
</table>
Questionnaire respondent characteristics: socio-economic groups:
The graph below shows the overall distribution across 5 socioeconomic groups (measured by postcode analysis and categorized into Scottish Index of Multiple Deprivation Quintile scores, where 1= highest and 5= lowest).

Questionnaire respondent characteristics: overall health:

<table>
<thead>
<tr>
<th></th>
<th>Good</th>
<th>Fairly Good</th>
<th>Not Good</th>
<th>Missing</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>75 (53%)</td>
<td>55 (39%)</td>
<td>9 (6%)</td>
<td>3 (2%)</td>
<td>142</td>
</tr>
<tr>
<td>Female</td>
<td>37 (47%)</td>
<td>37 (47%)</td>
<td>0 (0%)</td>
<td>4 (5%)</td>
<td>78</td>
</tr>
<tr>
<td>Total</td>
<td>112 (51%)</td>
<td>92 (42%)</td>
<td>9 (4%)</td>
<td>7 (3%)</td>
<td>220</td>
</tr>
</tbody>
</table>

Question: Over the last twelve months would you say your health has on the whole been:
**Questionnaire respondent characteristics: cardiac history:**
Members reported a wide range of cardiac conditions. Approximately half of all members reported a history of at least one heart attack, and about half had also undergone some cardiac surgery (most commonly bypass surgery). For the majority of conditions, a higher percentage of men than women reported the condition.

<table>
<thead>
<tr>
<th>Medical condition</th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>M.I.</td>
<td>84 (60%)</td>
<td>26 (33%)</td>
<td>110 (50%)</td>
</tr>
<tr>
<td>Hypertension</td>
<td>79 (56%)</td>
<td>39 (50%)</td>
<td>118 (54%)</td>
</tr>
<tr>
<td>Angina</td>
<td>87 (61%)</td>
<td>30 (38%)</td>
<td>117 (53%)</td>
</tr>
<tr>
<td>Heart murmur</td>
<td>12 (8%)</td>
<td>7 (9%)</td>
<td>19 (9%)</td>
</tr>
<tr>
<td>Abnormal heart rhythm</td>
<td>28 (20%)</td>
<td>13 (12%)</td>
<td>41 (19%)</td>
</tr>
<tr>
<td>Other heart trouble</td>
<td>25 (17%)</td>
<td>5 (6%)</td>
<td>30 (14%)</td>
</tr>
<tr>
<td>Surgery/ operation</td>
<td>91 (64%)</td>
<td>26 (33%)</td>
<td>117 (53%)</td>
</tr>
</tbody>
</table>

**Questionnaire respondent characteristics: length attendance:**

<table>
<thead>
<tr>
<th>How long have you been attending the group? (n=207)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Minimum</td>
</tr>
<tr>
<td>---------</td>
</tr>
<tr>
<td>1 month</td>
</tr>
</tbody>
</table>
Questionnaire respondent characteristics: living circumstances:
The table below summarises the living circumstances of questionnaire respondents. Most lived with other people, most commonly their spouse or partner but sometimes including their children. A higher proportion of women than men lived by themselves.

<table>
<thead>
<tr>
<th>Do you live with another person/ other people?</th>
<th>Yes</th>
<th>No</th>
<th>Missing</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>130 (92%)</td>
<td>12 (8%)</td>
<td>0</td>
<td>142</td>
</tr>
<tr>
<td>Female</td>
<td>52 (67%)</td>
<td>25 (32%)</td>
<td>1</td>
<td>78</td>
</tr>
<tr>
<td>Total</td>
<td>182 (83%)</td>
<td>37 (17%)</td>
<td>1</td>
<td>220</td>
</tr>
</tbody>
</table>

Questionnaire respondent characteristics: willingness to participate in qualitative study:
Approximately 80% of the screening questionnaire respondents were prepared to take part further in the qualitative phases of the study.

<table>
<thead>
<tr>
<th>Willingness to take part in focus group discussion</th>
<th>Yes</th>
<th>No</th>
<th>Missing</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>117 (82%)</td>
<td>25 (18%)</td>
<td>0</td>
<td>142</td>
</tr>
<tr>
<td>Female</td>
<td>52 (67%)</td>
<td>22 (28%)</td>
<td>4 (5%)</td>
<td>78</td>
</tr>
<tr>
<td>Total</td>
<td>169 (77%)</td>
<td>47 (21%)</td>
<td>4 (2%)</td>
<td>220</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Willingness to take part in one-to-one interview</th>
<th>Yes</th>
<th>No</th>
<th>Missing</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>123 (87%)</td>
<td>19 (13%)</td>
<td>0</td>
<td>142</td>
</tr>
<tr>
<td>Female</td>
<td>55 (71%)</td>
<td>18 (23%)</td>
<td>5 (6%)</td>
<td>78</td>
</tr>
<tr>
<td>Total</td>
<td>178 (81%)</td>
<td>37 (17%)</td>
<td>5 (2%)</td>
<td>220</td>
</tr>
</tbody>
</table>
**Qualitative study: focus group composition:**

<table>
<thead>
<tr>
<th></th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group A</td>
<td>5</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Group B</td>
<td>6</td>
<td>5</td>
<td>11</td>
</tr>
<tr>
<td>Group C</td>
<td>4</td>
<td>4</td>
<td>8</td>
</tr>
<tr>
<td>Group D</td>
<td>3</td>
<td>2</td>
<td>5</td>
</tr>
</tbody>
</table>

**Qualitative study: interview participants: age and gender:**

As can be seen from the table below, a wide range of participant ages were represented in the interview sample, but the average age remained in the early to mid-sixties, approximately similar to the overall average age across groups.

<table>
<thead>
<tr>
<th>Age (years) (n=27)</th>
<th>Minimum</th>
<th>Maximum</th>
<th>Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>16</td>
<td>82</td>
<td>61.4</td>
</tr>
<tr>
<td>Female</td>
<td>45</td>
<td>81</td>
<td>65.6</td>
</tr>
<tr>
<td>All</td>
<td>16</td>
<td>82</td>
<td>63.2</td>
</tr>
</tbody>
</table>

**Qualitative study: interview participants: Length group attendance:**

<table>
<thead>
<tr>
<th>Length group attendance (n=24)</th>
<th>Minimum</th>
<th>Maximum</th>
<th>Approx. Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>8 months</td>
<td>15 years</td>
<td></td>
<td>5 years</td>
</tr>
</tbody>
</table>