



Heart Support Group Reaffiliation 2014 Results

Heart Support Group Reaffiliation takes place annually and is an opportunity for the British Heart Foundation (BHF) to gather information about the affiliated Heart Support Groups (HSGs). As well as collecting up-to-date contact details, we gather information such as number of members in each group, how long they have been running and the type of activities they run.

This year, we asked some additional questions about how groups and their members (whether as part of the group or individually) work to influence local health and care services. These responses will help inform how we can better support those involved in campaigning and influencing in the future.

Overview:

- At the time the data was collated (August 2014), there were 277 HSGs affiliated to BHF.
- The response rate for completion of the form (for the same time period) has increased by 6.77% from 2013.

Group Membership:

- From the 227 groups who responded to this question, there is an estimated total combined membership of **30,569 HSG members**. The true membership number of all groups (including 47 groups who did not answer this question and three groups who formed after reaffiliation started) will be higher.

Charity Status:

53 groups have reported that they are registered charities.

Table 1 shows the length of time that groups with charitable status have been running. The majority (75%) of these groups have been running for between 16 – 30 years.

It is safe to assume that as groups become more established, registering as a charity is something they consider. There is nothing to prevent a group from becoming a registered charity, but there are both advantages and disadvantages. The [Charity Commission website](#) provides some information on the restrictions and requirements of being a charity. You may also wish to talk to other HSGs who have already taken the decision to become a charity to get their viewpoint. If you would find this helpful, get in touch.

**FIGHT
FOR EVERY
HEARTBEAT**

Table 1: Length of time running for those who a registered charity

Years	Number of Groups
1 - 5 Years	4
6 - 10 Years	5
11 - 15 Years	4
16 - 20 Years	10
21 - 25 Years	18
26 - 30 Years	10
30+ Years	2

Number of members per group:

Table 2 shows the membership numbers of HSGs with numbers ranging from 4 to 2000 members. Some groups may be including non-active members (*i.e.* only on a mailing list) or could refer to number of website visits per day as some are internet based groups. If you'd like to get advice from groups who have a large membership number to help your group, get in touch.

Table 2: Membership Numbers

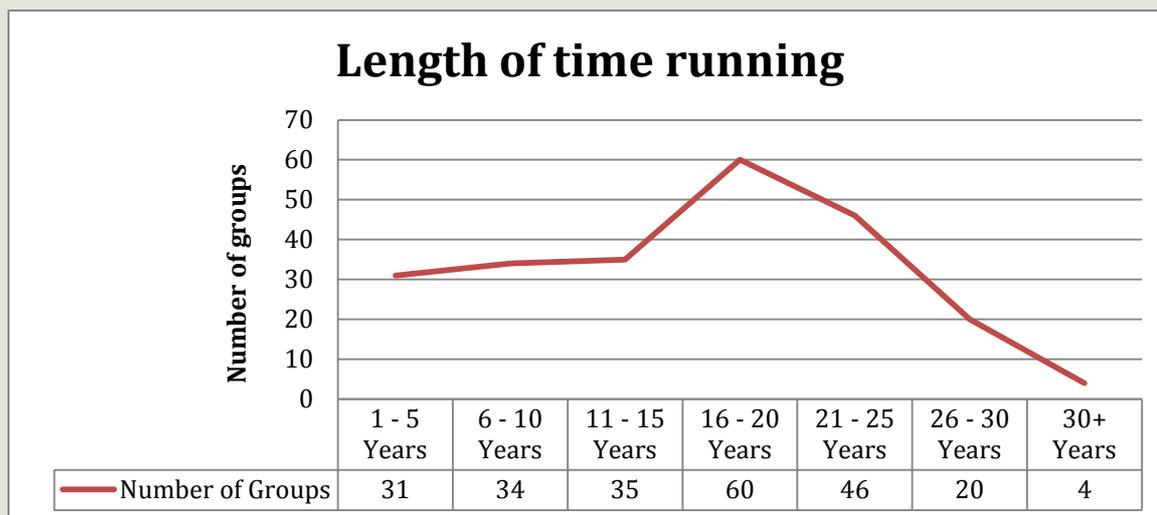
Number of Members	Number of Groups
< 20	42
21 - 30	27
31 - 40	27
41 - 50	14
51 - 100	42
101 - 200	36
201 - 300	17
301 - 500	12
> 500	11

Length of time groups have been running:

230 groups answered this question and from these groups it was found that the mean number of years a group has been running is 16 years and 1.5 months (16.12 years).

Figure 1 provides a graphical view of the number of years HSGs have been running and shows that after reaching a peak at 16-20 years, the number of groups decline.

Figure 1: Length of time groups have been running



The low number of groups running for more than 20 years could be explained by a number of reasons. These groups may have difficulty in recruiting new members and also recruiting members to take up roles which require more responsibility. In groups that have been running for a long period of time it is possible that the average member age is higher as well.

Cardiac rehab classes:

113 HSGs (out of 229 groups who responded to this question) have stated that they are running Phase 4 cardiac rehabilitation classes – 49.34%. Many groups are passionate about the need for patients to continue to exercise after leaving hospital.

Group activities:

HSGs provide support to their members in various different ways. For example, some wish to do only exercise classes or only social activities whereas others do a mixture of activities, including campaigning and providing a patient perspective for local NHS organisations.

In the reaffiliation form, groups were asked to select the activities they run for their members from a list of options. Table 3 and Figure 2 shows the number and percentage of groups who offer various activities, respectively, with Figure 3 showing the number of groups who provide more than one activity.

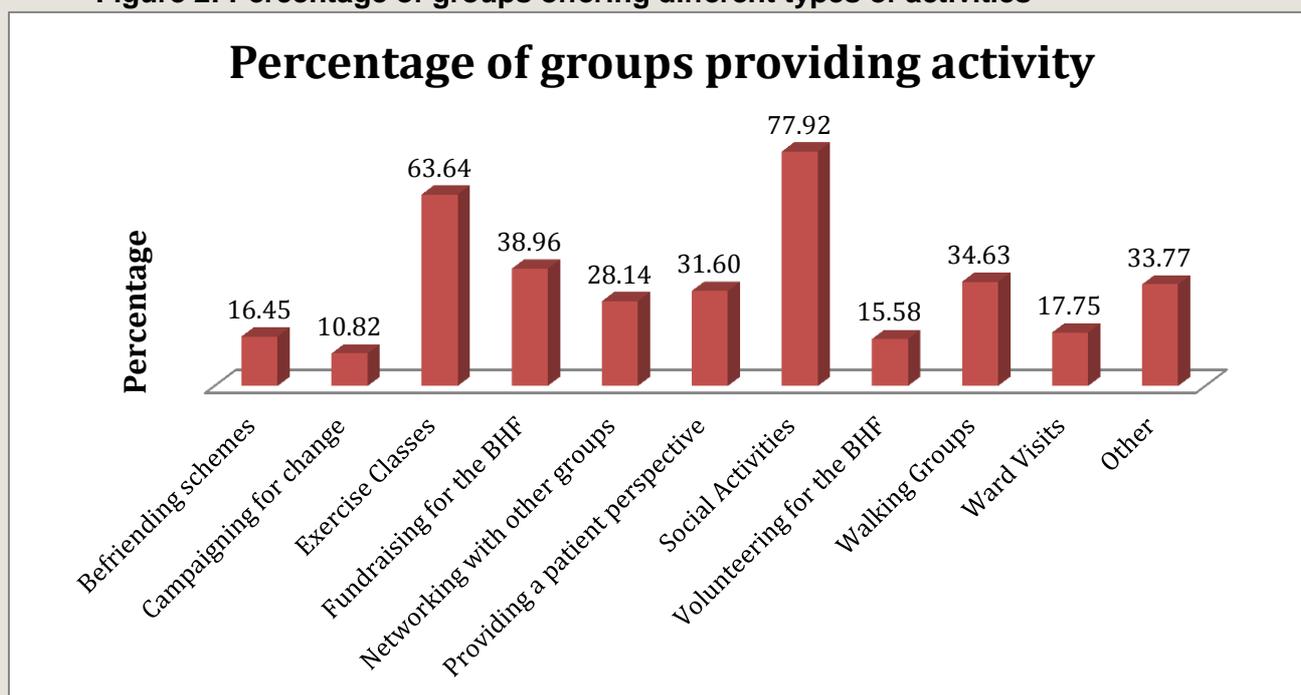
Table 3: Number of groups offering different types of activities

Activity	Number of Groups
Befriending schemes	38
Campaigning for change	25
Exercise Classes	147
Fundraising for the BHF	90

Networking with other groups	65
Providing a patient perspective to your local NHS organisation	73
Social Activities	180
Volunteering for the BHF	36
Walking Groups	80
Ward Visits	41
Other	78

As shown by Table 3 and Figure 2 (below), 'Social activities' is the most common activity but it does cover a wide range including visits, trips and dinners.

Figure 2: Percentage of groups offering different types of activities



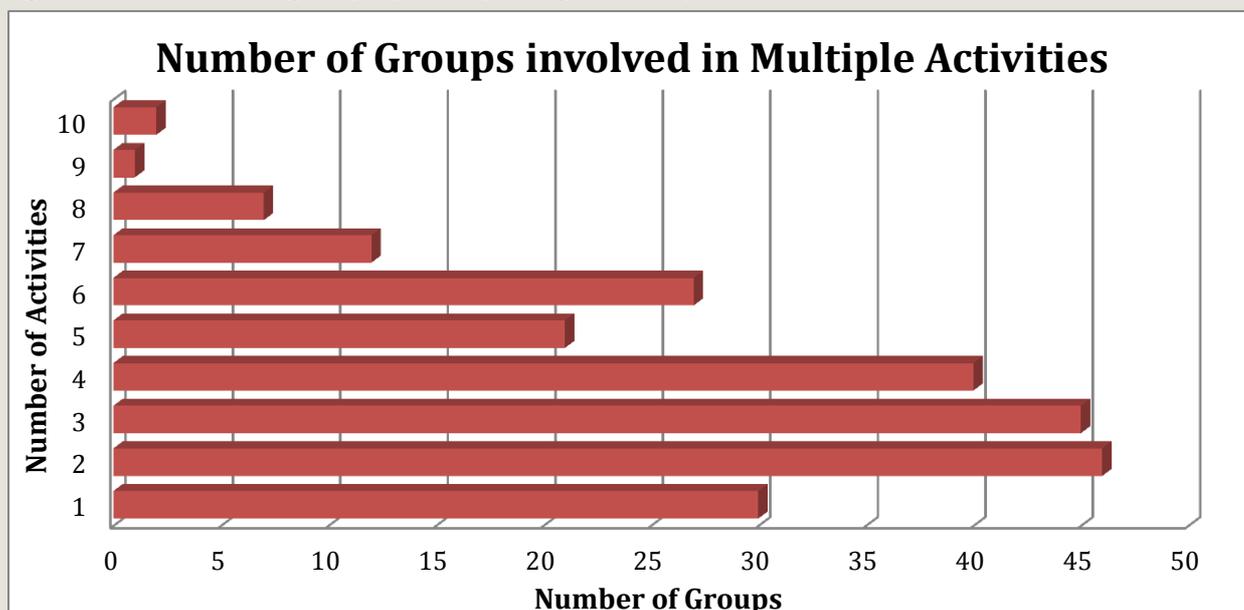
The 'other' category represents around $\frac{1}{3}$ of responses. These activities include, but are not limited to:

- telephone / online support
- fundraising for local services and group itself
- dancing classes
- holidays
- providing newsletters
- educational meetings
- meetings (usually monthly) with guest speakers.

From Figure 3 (next page) we can see that some HSGs offer a choice of activities for their members – 121 groups offer between one and four activities. Providing more choice means people are more likely to find something that is suited to them and are therefore able to get the support they need from their local HSG.

Note: ‘Other’ activities have not been included in the analysis for number of groups participating in multiple activities.

Figure 3: Number of groups participating in multiple activities



Influencing local health and care services:

This year groups were asked about their involvement in campaigning and influencing local services. A number of choices were provided for groups to select which services they are involved with – an ‘other’ option was also included.

115 groups are involved in campaigning and influencing local services in association with one or more organisations. Table 4 shows the number of groups whose members are patient / carer representatives or lay members in various organisations. Some are involved in more than one organisation.

Table 4: Number of groups involved in organisations to influence services

Organisation	Number of Groups
Cardiovascular Strategic Clinical Network	24
Health & Wellbeing Board	11
Healthwatch	16
Local Authority	15
Local Clinical Commissioning Group	22
Local GP Practice Patient Participation Group	41
Local Hospital	57
NHS Foundation Trust Member	42
Other	25

Examples of the ‘other’ organisations include:

- National Institute for Health and Care Excellence
- Cardiovascular Care Partnership UK

- BACPR Council
- Cardiovascular Clinical Network Steering Group
- Torfaen Voluntary Alliance
- Heart Voices

Campaigning for change with the BHF:

Out of the 211 groups who responded to the question *'have you ever campaigned for change with the BHF?'* 24 groups said yes.

Nine groups were involved with lobbying events in Parliament and two had stated they had written to their local MPs (as advised by BHF). Three had signed petitions for various campaigns, including getting defibrillators in public spaces and schools. Other ways that groups have been involved include being involved in the cardiac consultation with BHF and campaigning for expanding equipment in cardiac rehab.

Campaigning for change without the BHF:

From the 211 groups who responded to the question *'have you ever campaigned for change on your own or with another organization?'* 25 groups said yes. However, it was not always the same groups who responded or answered 'yes' to both questions.

Three of the groups worked specifically on ensuring the prevention of the reduction / closure of their local cardiac rehab services. The other responses related to groups providing a patient perspective and working with other organisations to raise general awareness of CVD and help develop services – largely at local level.

These organisations include (but not limited to):

- local hospitals
- local Patient Engagement Groups
- local CCGs and CCG Stakeholder Forum
- Black Country Cardiovascular Network
- National Council for Palliative Care
- BACPR Council
- other local support groups

Through reaffiliation we have found that whilst some groups may not be involved in campaigning / influencing, individual members might – working outside the remit of the group. Individuals who want more support and opportunities to influence local services can sign up to our [Heart Voices](#) network.

Helping groups campaign for change:

23 groups had provided suggestions as to how the BHF can help them campaign for change. Ten had said that they would like us to continue to / have more regular contact with them about new opportunities as well as getting this information out in the general public.

Seven groups would like us to better promote cardiac rehab and Phase IV classes and the importance of continuing exercise and physical activity. Two of these groups specifically want us to work with GP surgeries / healthcare professionals to ensure this happens.

Other responses were more specific e.g. help to campaign for improved waiting times for treatment and help to develop ways of collecting feedback following discussions with Hospital Trusts / CCGs.

Achievements in campaigning and influencing:

14 groups told us about their key achievements in this area.

One group successfully campaigned for PADs to be available in their local town (Calderdale) whilst another has helped to prevent cutbacks in cardiac rehab services. Raising awareness of cardiac rehab to prevent reduction in these services has played a part in a number of groups' successes.

Some groups have been working with other organisations to implement change. For example, one group has worked with North Lincolnshire County Council to initiate a 'Walking your way to health' scheme. Other HSGs have provided their perspective to local CCGs, regional Cardiac and Stroke Network Boards and also met with local councillors.

Group Achievements:

71 groups provided information about their key achievements which include, but are not limited to:

- Recruiting more from the local community rather than hospital referrals.
- Reducing membership decline and also having recruitment drives.
- Providing defibrillators for Phase 4 groups and public places.
- Raising funds for classes, equipment, local services and BHF.
- Raised funds to equip town with AEDs and trained 80 people to use them.
- Sponsored a graduate to obtain a BACPR qualification – help with shortage of qualified instructors.
- Raising awareness of the HSGs in the local community and improving links / relationship with local hospitals / cardiac rehab teams.
- Showcasing work at local health events – e.g. taking part in Chelmsford City Council CVS Health & Wellbeing Show.
- Winning awards:
 - Salford Heart Care - Queen's Award for Voluntary Service 2014.
 - Founder of Hailsham Heathfield Herstmonceux & District Cardiac Support Group - Chris Copsey Gold Award 2013.

Our communication with groups:

60 groups responded to the question asking how we could improve the communication between BHF and HSGs.

35 of these groups were happy with the current format and frequency and two, in particular, were pleased we had taken on board their feedback - *'The newsletter is most appreciated in response to the recent feed-back exercise. Thanks'*.

From the 25 groups who provided comments / suggestions, five expressed a need to clarify the best points of contact as well as having more personal contact from the BHF – e.g. in the form of a visit.

The remaining comments were more specific for that particular group and have been handled individually.

Next Steps:

- Use data from reaffiliation to compile a HSG Directory.
- Use the information around groups' work in campaigning and influencing to ensure they are receiving the support they need and to help develop BHF's plans in this area.