



## Heart Support Group Reaffiliation 2015 Results

Heart Support Group (HSG) Reaffiliation takes place annually and for the first time we used Grant Tracker (online system) to collect the data. Reaffiliation is an opportunity for the British Heart Foundation (BHF) affiliated groups to tell us about the work they've been involved in, the activities they run, their achievements and any issues they may be experiencing.

This year we asked additional questions about group's fundraising activity (for the BHF, the HSG itself and other causes).

### Overview:

- At the time of writing this report there were 264 affiliated HSGs.
- We had an 87.8% response rate - increased by 5% from 2014 for the same time period.

### Reaffiliation on Grant Tracker:

- This is the first time reaffiliation has been completed on Grant Tracker. A large number of groups had difficulty using the system and as such BHF received a high level of enquiries.
- We acknowledge that it was frustrating for many groups and will be using the feedback to make next year's reaffiliation a much smoother process.

### Group membership:

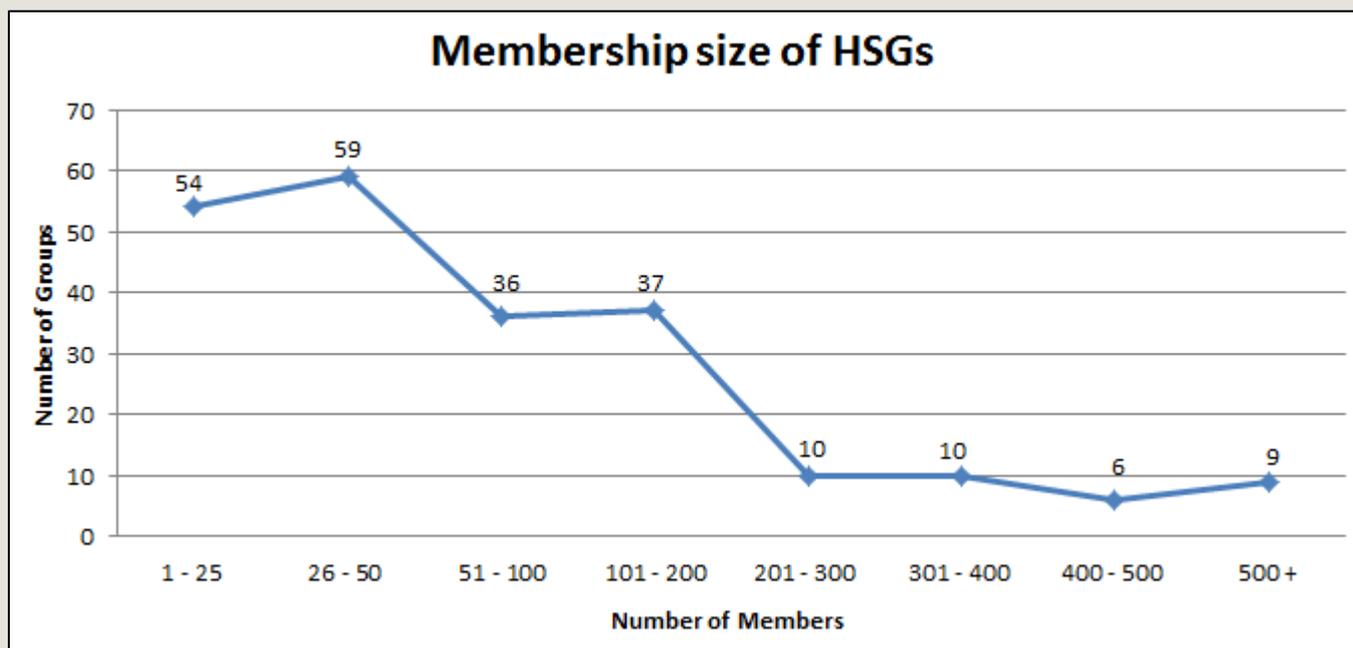
From the 221 groups who responded to this question, there is an estimated total combined membership of **29,158 HSG members**. The true membership number of all groups will be higher as this figure does not include the 33 groups who did not answer this question and the nine groups who were not due for reaffiliation.

The size of the groups varies significantly and ranges from 5 to 1394 members. However, it is important to note that the definition of 'member' varies between groups, e.g. for some it may be those subscribed to their mailing list, whereas others may define a member as someone who regularly participates in group activities.

The majority of groups have between 1 – 50 members. These include patients, carers and in some cases, healthcare professionals. If your group is struggling with attracting new members and would like to talk to one of the larger groups please [let us know](#) and we'll see if we can put you in touch with one of these groups for some advice.

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Figure 1: Number of members in HSGs

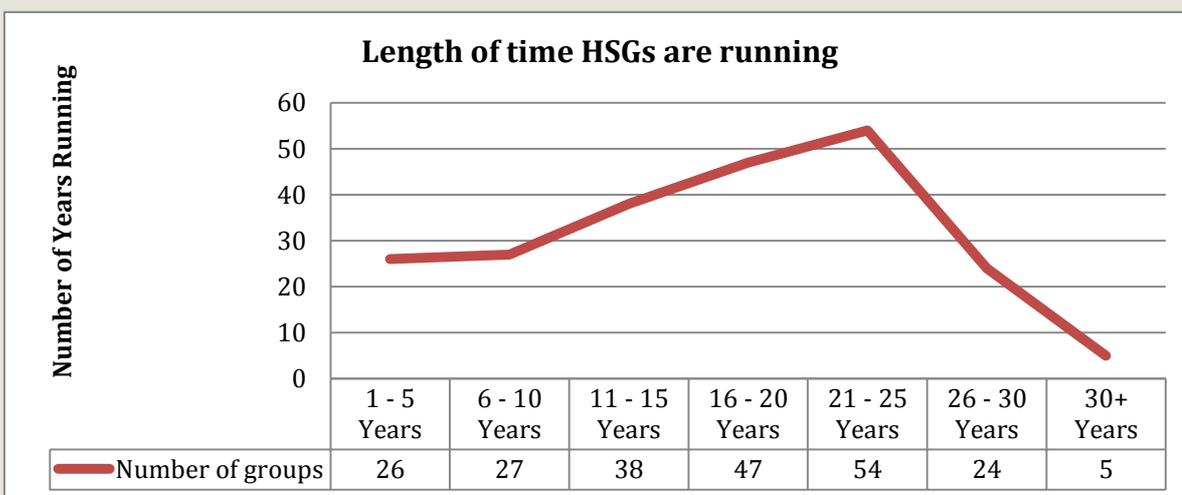


You may be interested to know there is a [BHF branded Heart Support Group Promotional Poster](#) that you can download from our website which has space for you to add contact details for your group. These posters are also on display on the community boards in the BHF Shops – introduce yourself at your local shop and get your contact details up on the Shop HSG poster. Don't forget there may be more than one local group so you may need to share this poster space.

**Length of time HSGs have been running:**

Figure 2 provides a graphical representation of the number of years HSGs have been running. It shows that after reaching a peak at 21 - 25 years there is a rapid decline in the number of groups that exist. The average number of years a group has been running is just over 17 years (17 years and 1 month).

Figure 2: Length of time groups have been running



13% of groups, who completed reaffiliation, have been running for 26 years or more. The decline in groups older than 25 years could be due to a number of different factors but there have been some common themes amongst the groups that have closed down.

The most frequently named reason for the group disbanding is lack of members. This is due to members not being able to attend because of health issues and also being unable to recruit new members. This, in turn, has meant groups are also finding it increasingly difficult to find members to take on committee roles.

### **Charity Status:**

49 groups have reported that they are registered charities.

Table 1 shows the length of time each of the groups who have reported a charitable status have been running. As in previous years, the majority of groups who have charity status have been running for a significant period of time – 78% have been running for at least 16 years. A number of groups have found gaining charity status can further develop the group and help them be in a more advantageous position for funding.

**Table 1: Length of time running for those who are registered charities**

| <b>Years</b> | <b>Number of Groups</b> |
|--------------|-------------------------|
| 1 - 5        | 4                       |
| 6 - 10       | 2                       |
| 11 - 15      | 5                       |
| 16 - 20      | 5                       |
| 21 - 25      | 18                      |
| 26 - 30      | 13                      |
| 30+ Years    | 2                       |

The [Charity Commission](#) is a good place to start when considering whether or not to become a charity in your own right. Some groups have told us that whilst their advice is very practical it does not necessarily give them a better understanding of what becoming a charity will entail. If you are interested in finding out more about obtaining charity status then [let us know](#) and we will try to put you in touch with other HSGs who have gone through the process themselves.

### **Cardiac rehab classes:**

99 HSGs have stated that they are running Phase 4 cardiac rehabilitation classes – 44.79%. Please note, if you are running Phase 4 classes you will need a BACPR qualified instructor. This is to ensure that the instructor offers a safe and appropriately leveled exercise programme for HSG members.

**Note:** Classes that are not categorized as Phase 4 do not need a BACPR instructor but should have an instructor with his / her own insurance cover.

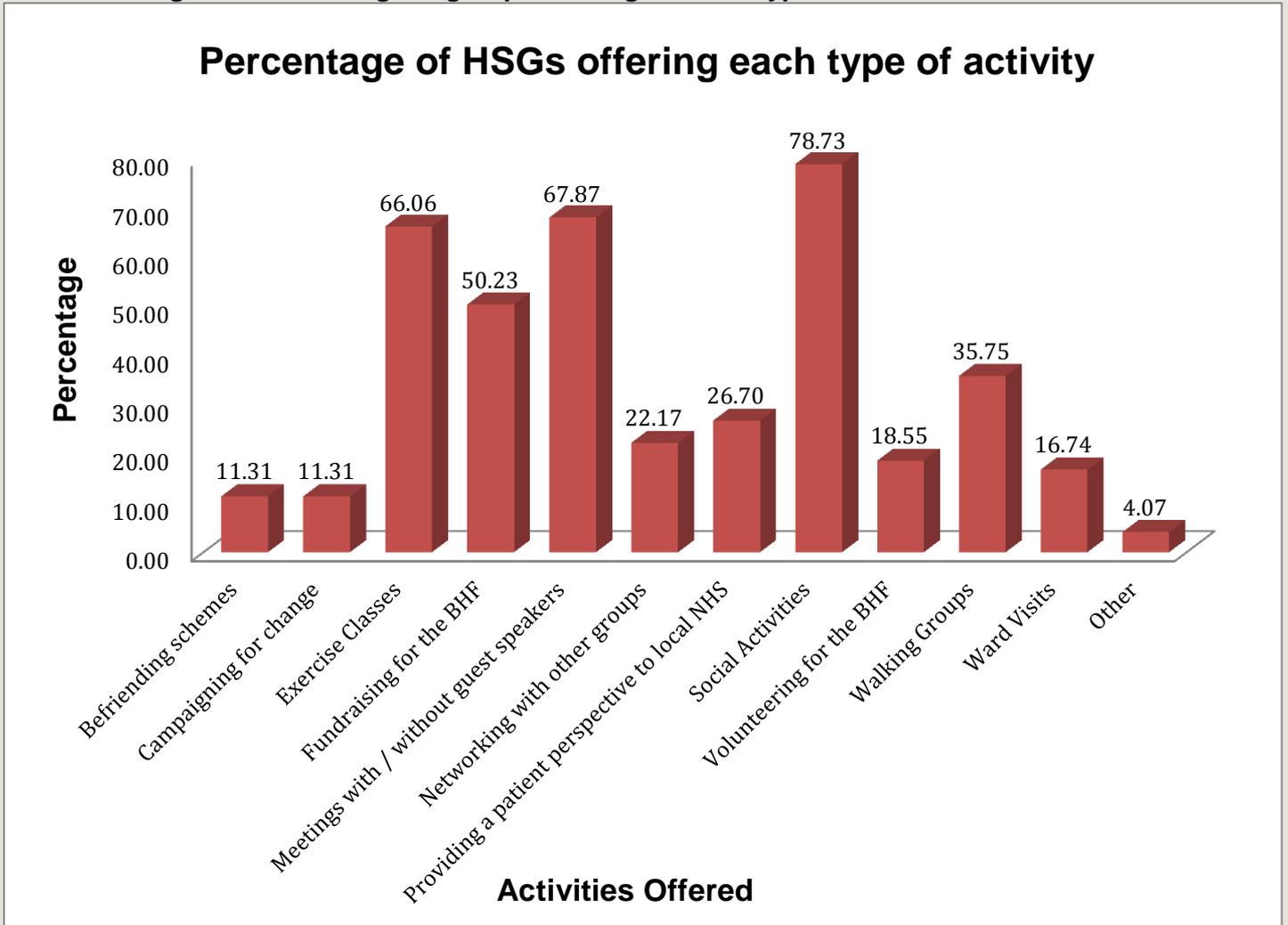
### **Group activities:**

HSGs offer a variety of activities for their members to get involved in such as exercise classes, social activities or campaigning. Some groups may choose to only offer one type of activity while others choose to provide a range.

In the reaffiliation form, groups were asked to select which activities they provide from a list.

Figure 3 show the percentage of groups that offer various activities whilst Figure 4 shows the number of groups who provide more than one activity.

**Figure 3: Percentage of groups offering different types of activities**



The 'other' category includes, but is not limited to:

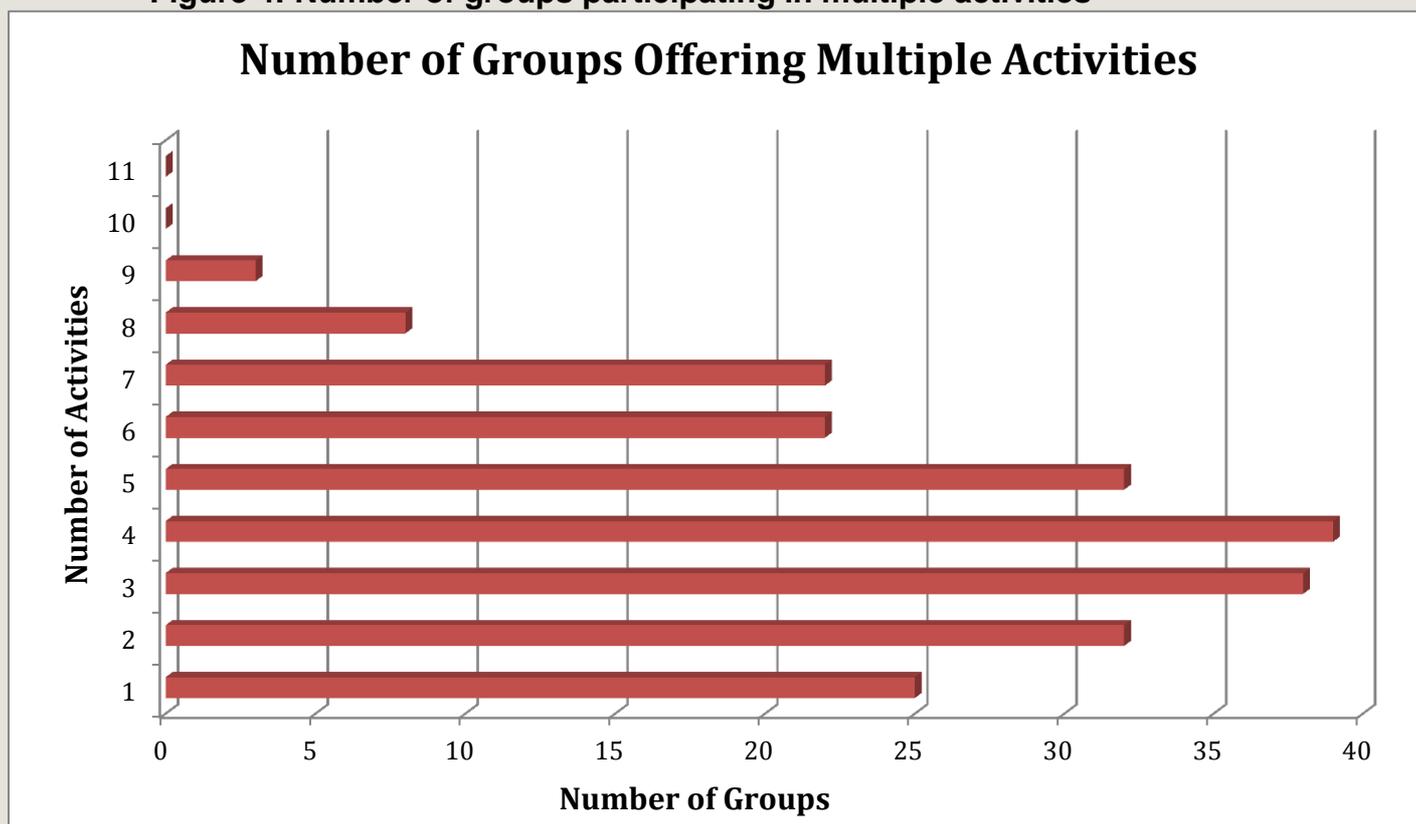
- buddy groups
- education days
- CPR training
- awareness sessions at public events
- assisting with training of newly qualified doctors at the local hospital

'Social activities' has shown to be the most popular activity on offer (78.73% of groups provide this) but it does cover a number of different types of activity such as day trips, dinners and coffee mornings. The number of groups offering exercise classes is also quite high (66.06%) which shows one of the key aspects that people want from support groups is finding ways to keep fit. Types of exercise classes include swimming, dancing and badminton amongst others.

'Meetings with / without guest speakers' was not an option previously provided but it has shown to be the second most common activity on offer (67.87% of groups). Groups have indicated that they like to meet on a regular basis to catch up with other members and also have the opportunity to hear from speakers about a variety of topics and learn something new.

Two common enquiries from groups is whether BHF can send someone to attend their meeting to provide an overview of BHF and whether we have a list of potential guest speakers in their local area they can approach. At the moment we are not in a position to help in these situations. However we do suggest you get in touch with local HSGs and share contacts for speakers or even offer to speak at their meeting in return for them speaking at your meeting. If you'd like details of local HSGs have a look at the online [HSG Directory](#) (separated by region).

**Figure 4: Number of groups participating in multiple activities**



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

Figure 4 shows that HSGs offer a variety of activities and about 60% of groups offer between one and four different activities. When looking more closely at the data we found there wasn't a correlation between number of activities on offer and the number of members in the groups or the length of time the group has been running. This would suggest offering up to four different activities would provide an adequate range to ensure different group member needs are met.

### **Heart Support Groups and Fundraising:**

This year groups were asked about their work in fundraising including the activities they used to fundraise and how much money they raised. They were asked about whether they fundraise for BHF, for themselves (to keep the group running), their local NHS organisation or any other cause.

We're aware that some individuals are members of both the HSG and their local BHF Fundraising Group but this is not information that has been collected.

### **Fundraising for BHF:**

98 groups told us they fundraised for BHF and have done this in a number of different ways. Some have got involved in BHF's different fundraising events such as the London to Brighton and London to Southend bike rides, fundraising walks at the Tower of London and challenges such as Dechox.

Others get involved, year after year, with 'Bag it. Beat it.' and 'Wear it. Beat it' as well as hosting a number of different 'red - themed' events or challenges. A few groups also got involved with the bucket collection for the Tesco partnership in February. The majority of groups who fundraise for BHF do so through BHF run events.

A few other common methods used to fundraise for the BHF include:

- raffles
- stall at local fair
- coffee mornings
- sponsored walks / runs
- donations to local BHF shops
- specific events – e.g. annual Cardiac Olympics

The amounts raised ranged from £100 to £3200 over the last year. Some groups stated that they would fundraise more for BHF if the group was bigger and/or members were more able.

### **Fundraising to keep the HSG running:**

109 groups have said that they fundraise to keep the group running. A number of the methods used were the same as those used to fundraise for BHF. Some common approaches include:

- raffles
- coffee mornings / tea bars / bake sale
- bingo nights / game nights
- quiz nights

- car parking services
- car boot sales / auctions
- sponsored activities e.g. sponsored walk or run
- organizing a local concert / fundraising at existing festivals and concerts
- holding stalls at a local fair or hospital
- collections at supermarkets and football clubs

A large number of groups ask for membership / attendance fees which are enough to cover the costs of running the group and so do not actively fundraise for their group.

A small portion of groups apply for grants or get help from other organisations. This includes one-off donations and longer term arrangements. Examples include donation matching from Lloyds local branch mortgage staff, funding from Big Lottery Fund, Comic Relief, Rotary Clubs and donations from local charities and their members.

If you would like advice from HSGs who have been successful in fundraising for themselves, [let us know](#), and we'll see if we can put you in touch with one of these groups.

#### Fundraising to help local NHS organisations:

65 groups fundraise to provide donations to their local NHS organisation – some provide a monetary donation while others offer equipment. The majority provide donations to the local cardiac unit but some are more specific to a particular condition e.g. heart failure.

Fundraising methods used are similar to those previously mentioned including raffles, stalls, sponsored challenges (e.g. sponsored walk), quiz nights, bucket collections and annual balls.

Donations have included:

- exercise bike / gym equipment for cardiac rehab team
- heart monitors / blood pressure monitors / ECG machines
- contributions towards a new coronary care unit
- specialist equipment (heart related) for infants
- projectors to be used in CPR training

#### Fundraising for another cause:

46 groups raise funds to donate to another cause other than BHF, their group or the local NHS. From the information we have, this has ranged from £40 to £3000 for a number of different causes. One group told us that each year their members choose a charity of the year to support.

St John's Ambulance is a common recipient of donations from HSGs. Others include:

- Macmillan Cancer Support
- Cancer Research UK (taking part in Race for Life)
- Stroke Support Group

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- Specific fundraising initiatives such as Nepal Earthquake
- Local Air Ambulance
- Food Banks
- Small local charities and hospices

#### Relationship with local BHF Fundraising and Volunteer Manager (FVM)

One of the roles of the BHF Fundraising and Volunteer Manager is to help and support those who are interested in fundraising for BHF.

27 groups have said they are in contact with / receive support from their local FVM whereas eight groups were unaware this post existed. Four groups did have a good relationship with their FVM but the individual left the organization. They either do not know if the post has been filled or are waiting to be approached by the new FVM. In these cases we are working to rectify the situation.

If you would like to talk to your local FVM to get ideas on how you can fundraise for BHF then [get in touch](#).

#### BHF help with fundraising activities:

19 groups have stated they would like our help with fundraising. Seven of these groups did not have any specific things they wanted from BHF but rather wanted some suggestions and (unusual) ideas on how to fundraise.

- Four groups have specifically said they would like the input of their local FVM.
- Three of the groups have indicated that they would like to raise funds for a specific reason – to buy a defibrillator, to pay rent and instructor fees and to raise funds for BHF.
- Three have specific requests about promotional materials e.g. having access to a branded poster and having the posters available in different sizes.
- Two would like the opportunity to share ideas with other groups and have access to clear examples of successful fundraising.

We are currently in the process of helping these groups with their individual requests. If your group is interested in getting more involved in fundraising then have a look at the [Top 10 Fundraising Tips](#) page on the BHF website or order the new [BHF Fundraising Pack](#) (available to order) – both of these will provide you with advice and guidance on moving forward with your fundraising goals.

#### Group Achievements:

177 groups told us about the work they've been involved in and things they've accomplished. The most common achievements were **keeping the group running and increasing membership**. Others include:

- Raising funds
  - to purchase defibrillators, AEDs and equipment for the local hospital
  - for the creation of an exercise DVD.

- Working hard to reinstate the local cardiac rehab services.
- Building relationships with the local cardiac rehab team who then refer patients to the groups.
- Setting up a group website and creating patient packs to give newly discharged patients.
- Running additional exercise classes or starting new activities – e.g. dance classes or a cardiac Olympic event.
- Raising awareness of different health conditions and running ‘Education Days’.
- Running CPR training sessions.
- Sharing views and experiences with different organisations – one group created a members advisory group to help achieve this.
  - Getting involved with local CCGs
  - Presenting to BACPR and CSP
  - Presenting to European Heart Forum
  - Took part in the NHS England research programme about the Patient Voice
- Committee member was asked to be involved in the recruitment of an Arrhythmia Cardiac Nurse Specialist.
- Winning awards:
  - Happy Hearts were nominated for the Wiltshire Health Awards.
  - Tickers Cardiac Exercise Group came third in the ‘Heart of Essex’ competition.
  - Chairman and Secretary of C.R.A.S.H. Heart Support Group were awarded the Carn Brea Parish Council Clarence Coombe Award for services to the community.

#### **Next Steps:**

- Use the information provided on the groups’ work in fundraising to help them get the support they need.
- Develop a plan of action to ensure next year’s reaffiliation on Grant Tracker is a much smoother process and groups are able to complete the form without much difficulty.