



Support group network conferences

In April 2016 two support group networking conferences were held in Swindon and in Manchester. Representatives from pulmonary fibrosis support groups across the UK attended. The conferences gave representatives a chance to network and learn from each other, take useful information back to their support groups and discuss the future of a UK-wide support group network.

Background information

Why did we organise these conferences?

We organised these conferences as we had feedback from some of the pulmonary fibrosis support groups that they would like to meet and talk to other groups from around the country. We've previously organised similar events for our Breathe Easy support groups (for anyone with any lung condition) and we've been told by the Breathe Easy groups that they are very useful.

How did we organise it?

We invited all pulmonary fibrosis support groups across the UK, including new ones that were in the process of being set-up. The conferences were funded by Boehringer Ingelheim (founding partner) and Roche.

Who took part?

Representatives from 21 different support groups across the UK attended one of the two conferences. We reached 64% PF support groups in the UK. Twelve groups did not manage to attend the meeting (this includes two groups that have not yet held their first meeting). We'll be inviting them to take part in the development of a UK wide support group network.

Group representatives attending

Bristol IPF Support Group	Manchester Pulmonary Fibrosis Support Group
Chorley Hospital representative	Northern Ireland North West Support Group
Derby Pulmonary Fibrosis Group	Northern Region IPF Support Group
Exeter Pulmonary Fibrosis Group	Oxford Pulmonary Fibrosis Support Group
Grampian Pulmonary Fibrosis Support Group	Papworth IPF Support Group
Hertfordshire Pulmonary Fibrosis Support Group	Royal Brompton Hospital Pulmonary Fibrosis Support Group
Hull and East Yorkshire Pulmonary Fibrosis support group	St Georges Hospital (London) Pulmonary Fibrosis Support Group
Leeds Pulmonary Fibrosis Support Group	Sutton Coldfield Support Group
Leicestershire Pulmonary Fibrosis Support Group	University Hospital of North Midlands Lung Fibrosis Support Group
Llandough Hospital Pulmonary Fibrosis Support Group	Wessex Interstitial Lung Disease Support Group
	Wigan and Leigh representative



What did the day look like?

We asked for ideas about what groups wanted to cover on the day. We didn't get much feedback on this, so we based the days on previous similar events we've held for Breathe Easy groups. One conference was held in the south in Swindon and one conference was held in the north in Manchester. Both conferences had the same programme, but different research presentations. To see a programme for the conference, go to Appendix 1.

Notes from discussions on the day

All about my group

Each group introduced themselves and told us what they had been up to.

There were so many varied activities that support groups had done including:

- Inviting a singing coach to come along.
- Inviting an expert to talk about how to breathe
- A talk on travelling, including flying and the medical you need
- Cheese tasting
- Going on a trip, for example Bletchley Park
- Having a computer workshop to learn how to use the internet
- Positive thinking workshop
- Visiting a garden centre
- A session on yoga
- Information on personal independence payments (PIPs) and other benefits

There were also different ideas about how the meetings could be structured:

- Everyone loves cake!
- Having a welcome session at the start, especially for new members
- Having a separate room for patients and carers to take time apart to talk to each other
- Teleconferencing across different sites when it is a rural group, using webinars (Northern Ireland are trialling this)
- Car sharing to get all members to the meetings
- Asking members to arrange one event for one of the meetings
- Making the meetings very interactive and interesting to encourage people to come back
- Holding a meeting in a different town occasionally to reach more people
- Setting up a buddy system for new members
- Holding the meeting at the hospital meant better access to hospital personnel

Some difficulties experienced included:

- Finding a meeting place at start, so lots of moving round
- Setting up a bank account, so many checks because not a charity
- Loss of friends and members
- Finding new and interesting activities
- Watching out for banking scams



Group members also told us about how being part of a support group helped them:

- Less alone
- More laughter lines and a little plumper
- Meeting so many other people and know you're not alone
- Looking forward to speakers and monthly meetings
- Knowing that you are not alone
- Patients want to know as much as they can, want to meet people and chat about their condition

If you'd like information and advice for your support group then you can phone up our team at the Helpline who will be able to help on 03000 030 555.

Creating and running a successful support group

The aim of this workshop was to focus on how to get people helping with creating and running a successful support group.

The discussion varied quite a bit between the two different meetings in Swindon and Manchester. At one meeting there was a strong opinion that support group committees were not needed as there was a health care professional to run the group. At the other meeting most groups were keen to have a committee to be able to have ownership of the group however they recognised that were difficulties getting a committee together and keeping it going. Having a committee can very much depend on how established a support group is, and whether the members volunteer to get involved.

The workshop then looked at how it is possible to break down the tasks that are needed to make a support group happen and to get people involved, even if there is not a committee.

Some of the tasks that are needed to make a support group meeting happen:

- Telling members about the meeting - newsletter, emails, post
- Having a contact list of all the members
- Having health care professional support to promote the group - consultants, nurses
- Contacting new members to make them feel welcome
- Finding out what group want - e.g. medical vs. social activities
- Organising tea/coffee/cake
- Organising speakers
- Welcoming speakers
- Supporting other members
- Planning the venue
- Someone to lead meetings

Some of the reasons that people don't want to get involved or help out:

- Too busy
- Choosing the right person/commitment
- Unpredictable condition
- Timing of meetings - evenings/day time



How we can help people to get involved with the running of a group:

- Members help with individual tasks, rather than being on a committee
- Building up confidence of members
- Being positive not negative
- Promoting the group to new members through press and local media
- Getting ILD nurse support or another health care professional
- Asking for volunteers from other local organisations to help, even if they do not have a connection with pulmonary fibrosis

If you'd like to hold a similar workshop with your support group and get my facilitator notes from the session then please get in touch at ipf@blf.org.uk. You can get your group members to think about what needs to be done to run a meeting and then get them more involved. Even help with smaller tasks can be really useful!

Support group monopoly

In this workshop we asked people to work in groups. We told each group they had a million pounds and they had to decide how they would like the money to be spent. We gave groups some different options with different costs and also the chance to think of anything else themselves. This generated a lot of discussion and the responses at the end were very different! Some groups wanted to spend all their money on research, while others spread their money across lots of different activities to provide support such as a Helpline, information events or helping ILD nurses.

Did you know that you can tell us to make sure any money you fundraise goes to pulmonary fibrosis? If you'd like to find out more about how you can take action you can visit www.blf.org.uk/take-action or give us a call.

Future of a UK pulmonary fibrosis support group network

In this session we asked everyone if they were interested in having a UK wide pulmonary fibrosis support group network, and if so what would they like this to look like. Most people said they would be interested in getting involved in a network, 21 attendees voted 'yes', one voted 'maybe', one voted 'don't know' and one voted 'no'.

Suggestions included:

- Yahoo type email groups
- Sharing contact details
- Drop down menu for groups on BLF website. (You can search for pulmonary fibrosis support groups and other groups in your area at www.blf.org.uk/support-in-your-area.)
- Visit each other's groups/exchange visits
- More events like this one
- What about other areas with or without groups?
- Specific forum on BLF website/Health Unlocked
- Written report on today's meeting



- Sharing electronic versions of posters
- Sharing ideas
- Email
- Twitter/Facebook (closed), but make sure it has a different reason than the current Facebook groups
- Online newsletter or email newsletter
- Representatives from each group to take part in network
- BLF visit each of the groups and reports back
- Webinars up-dated
- Annual/bi-annual meetings

ACTION! Please would each support group email me to tell me what their favourite top 5 ideas from this list are by 1st July 2016. If you have any other suggestions then let me know at ipf@blf.org.uk

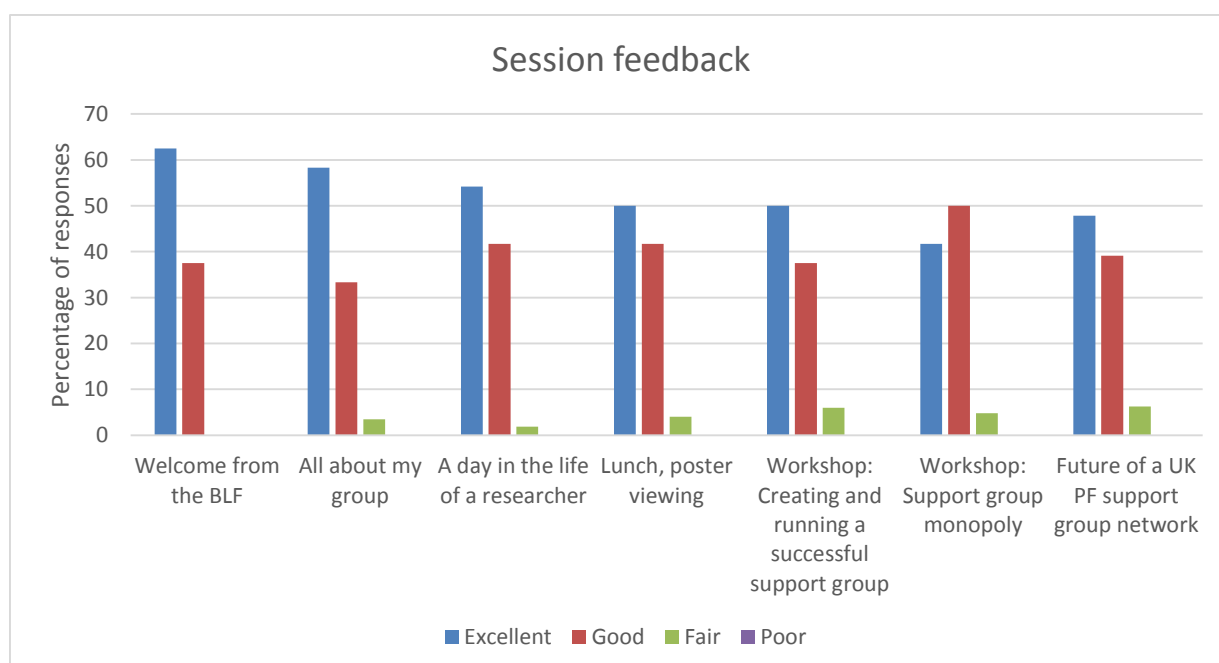
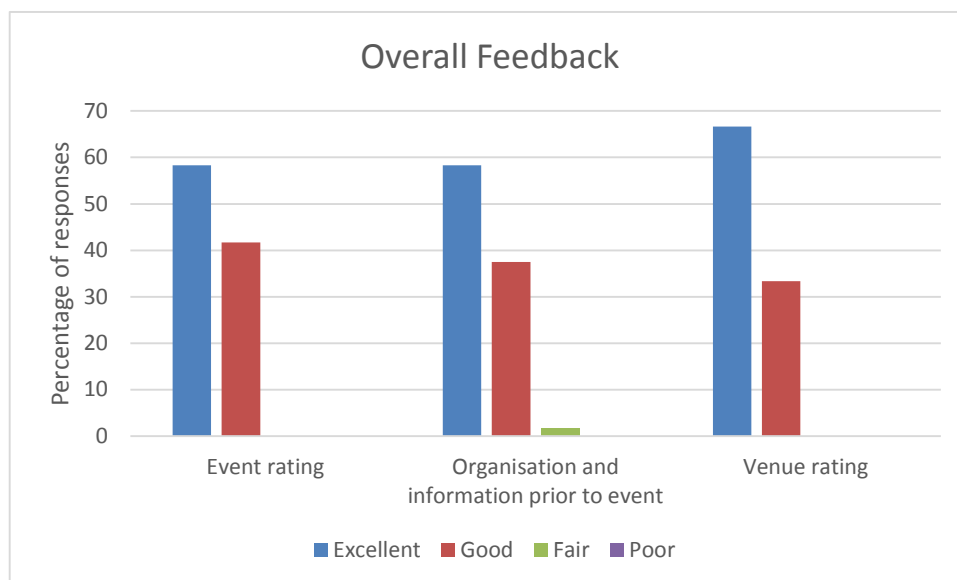
Feedback from the conferences

The support group networking conferences were well received. 58% of you rating the conferences as excellent while 42% rated them as good. All sessions were extremely well received with the most popular being in the morning - *'welcome from the BLF'*, *'all about my group'* and *'a day in the life of a researcher'*.

You told us that the most useful parts of the day were meeting and networking with other support groups, the research presentation, learning ideas to take back to your support group and information about the other groups from the poster presentations.

Suggestions for future work and how to improve similar conferences were considerably more varied with few themes coming through. Suggestions mainly focused on more information about research and more information about what other groups are doing.

"It was a very enjoyable and stimulating day. With your help, patients can do much to help and support each other - very empowering."





Appendix 1: Programme

Pulmonary Fibrosis Support Group Networking Conference **Sharing Experiences**

April 2016

- 11.00 am **Welcome from the British Lung Foundation**
- 11.15 am **All about my group: Introductions**
Introduce your support group with a poster
- 12.00 noon **Manchester: A day in the life of a researcher: In-depth focus on PF research**
OR Dr Wendy Funston, Clinical Research Associate, Institute of Cellular Medicine, Newcastle University
- 12.00 noon **Swindon: A day in the life of a researcher: In-depth focus on PF research**
Dr Franco Conforti, Research Fellow, Academic Unit of Clinical and Experimental Sciences Faculty of Medicine Southampton General Hospital
- 12.25 pm **Questions & Answers**
All
- 12.35 pm **Lunch, poster viewing & networking**
- 1.15 pm **Workshop: Creating and running a successful support group**
Group work
- 1.55 pm **Workshop: Support group monopoly**
Group work
- 2.35 pm **Future of a UK pulmonary fibrosis support group network**
All
- 3.00 pm **Close & Thank you**