

Customer feedback report 2015

Highlights and summary

At Parkinson's UK, our aim is to always put the views of people affected by the condition at the heart of everything we do. One of the ways we do this is through our feedback mechanisms. People are able to contact us and give us their views in numerous ways – online, email, telephone, in person and using our feedback cards – and we encourage people to talk to us using any of these channels.

This has enabled us to gather varied and important feedback from people affected by Parkinson's, which shapes our work and tell us how we're performing, in particular in our customer care practices. We're proud that so many people feel willing and able to share feedback with us, as the figures below indicate.

In 2015, Parkinson's UK received

- 2066 positive comments and compliments
- 199 neutral comments and suggestions
- 197 complaints
- 26 complaints were formal complaints, with 20 being upheld

Compliments

Compliments were received from across the UK and relating to all areas of the charity. Our Parkinson's Local Advisers consistently receive a high proportion of all compliments, indicating how valued their service is. Comment included:

"I found all the information provided was exactly what I needed."

Our helpline employment and benefit advisers also received numerous compliments too:

"Thank god for people like you and [Parkinson's UK] who must have hundreds of thousands of people to deal with, but you were never in a hurry. I never felt you were rushing me along although you must be inundated."

Our information resources continue to be commended by people affected by Parkinson's, people said they are "clear", "empowering" and "optimistic" in tone.

Complaints

We weren't always able to meet our expected high standard of customer care. The main areas of complaint were process related issues, including acknowledgement of donations. The report highlights all complaint themes. It also shows examples of learning – please see pages 8 and 11.

Customer feedback report 2015

This report provides an update on the key themes of customer feedback received during 2015 through our feedback channels – including online, emails, by phone and post and surveys.

Feedback received in 2015

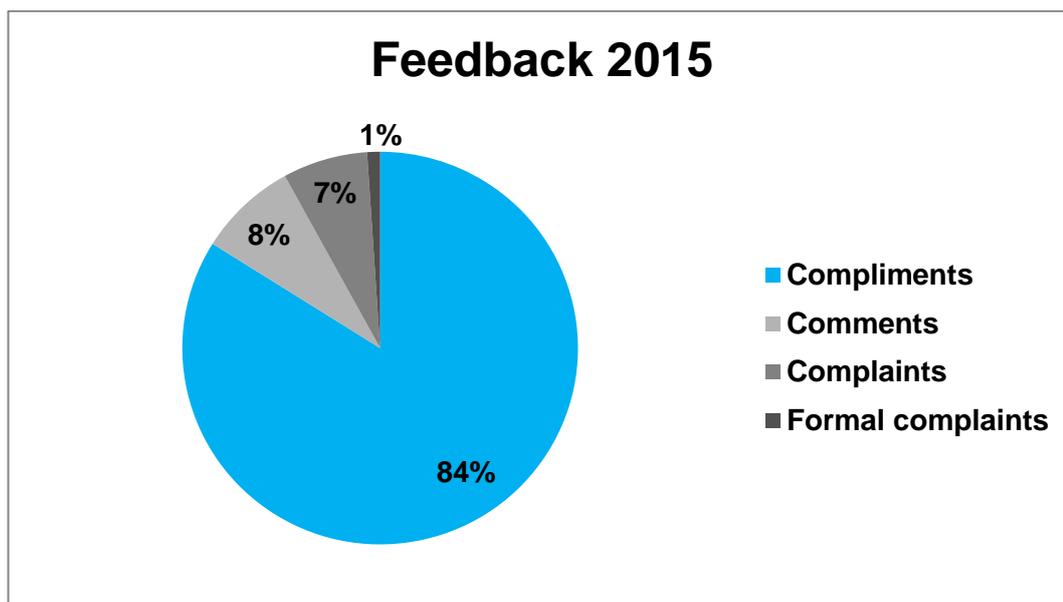


Figure 1: Feedback received – 2015

Definitions

Our 'feedback' includes:

- Comments/suggestions – people sharing their thoughts and/or what they think we can change
- Compliments – what people think we have done well
- Complaints – what people think we have done wrong

Activity in 2015

To provide some context, in 2015:

- the helpline answered 22,695 phone calls and responded to 3,260 email enquiries;
- the Parkinson's Local Adviser service received 13,067 referrals (8,250 new) and had over 80,000 customer interactions;
- fundraising campaigns and activities included
 - Direct Mail: 350,000 pieces
 - Email: 1.6m broadcast
 - Telephone: 5000 outbound conversations
- Information resources ordered: 594,581; PDF information resources downloaded from website: 288,953.

Breakdown of feedback received in 2015

In 2015, we received 2493 items of feedback in total of which, 2066 items were positive and/or complimentary.

| Feedback 2015 | Q1 | | | Q2 | | | Q3 | | | Q4 | | |
|-------------------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|--------------|
| | Jan | Feb | Mar | Apr | May | Jun | Jul | Aug | Sep | Oct | Nov | Dec |
| Comments | 7 | 20 | 10 | 11 | 15 | 7 | 21 | 24 | 18 | 24 | 27 | 15 |
| Compliments | 30 | 55 | 46 | 25 | 26 | 29 | 27 | 20 | 25 | 29 | 35 | 105 |
| Complaints | 6 | 21 | 23 | 14 | 13 | 8 | 11 | 6 | 7 | 2 | 7 | 14 |
| Formal Complaints | 0 | 2 | 0 | 8 | 2 | 3 | 2 | 1 | 4 | 2 | 0 | 2 |
| Total | 43 | 98 | 79 | 58 | 56 | 47 | 61 | 51 | 54 | 57 | 69 | 1789* |

Table 1: Breakdown of all feedback – 2015

*including a total of 1614 positive and 39 negative survey responses

The percentage of positive to negative feedback items was 91%.

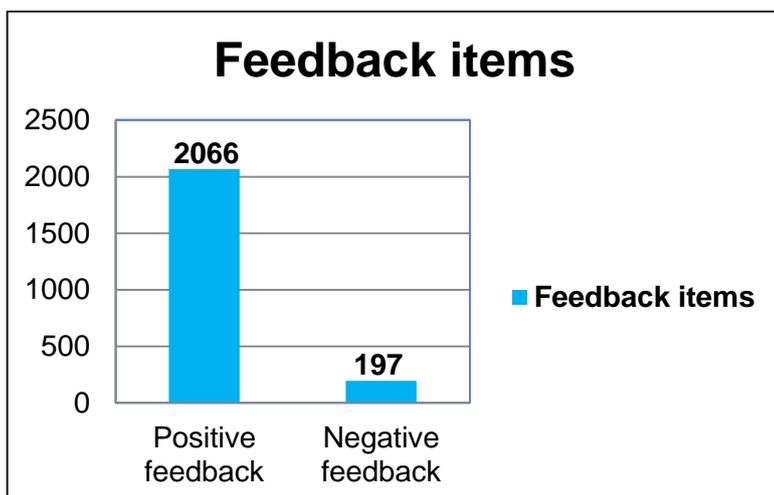


Figure 2: Number of positive feedback items versus negative items*

Comparison to previous years

Compared to 2014, our percentage of positive to negative feedback increased, 89% to 91% positive. We are well in our target of no more than 25% negative feedback as shown in Table 2 below.

| Year | 2011 | 2012 | 2013 | 2014 | 2015 |
|--------|-------|-------|-------|-------|-------|
| Target | < 25% | < 25% | < 25% | < 25% | < 25% |
| Actual | 20% | 17% | 14% | 11% | 9% |

Table 2: Percentage of negative to positive feedback since 2011

There has been a consistent increase in positive feedback since 2011. This can be explained in numerous ways: we have made it easier for people who use our Parkinson’s Local Adviser service to provide feedback using the feedback card and so have noticed an increase in this area. Also, we are more proactive than ever in going out to people and seeking their views

(eg. evaluations) Finally, we have encouraged staff to share more customer feedback by promoting our feedback processes amongst staff throughout the year. Improvements have already been noted.

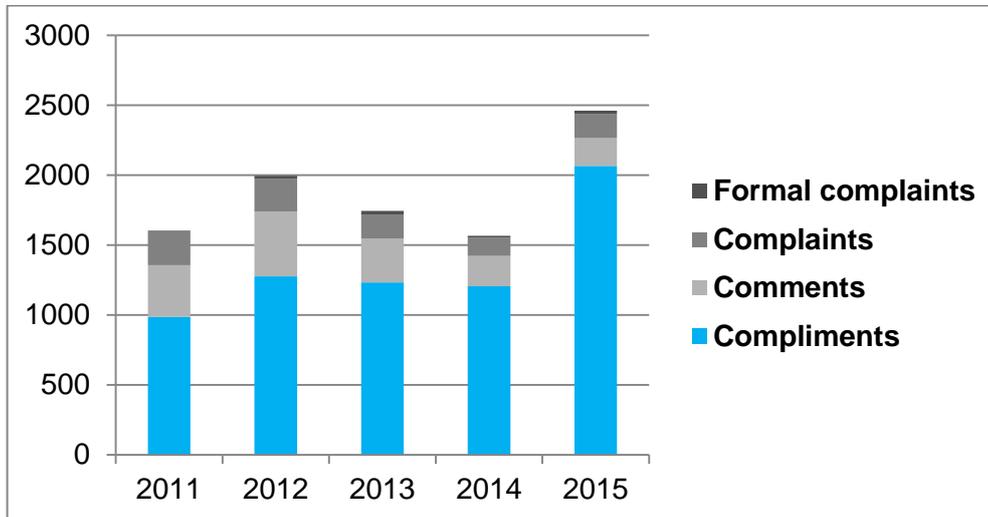


Figure 3: Breakdown of all feedback items over the last 5 years

| Feedback | 2011 | 2012 | 2013 | 2014 | 2015 |
|--------------------------|-------------|-------------|-------------|-------------|-------------|
| Compliments | 985 (61%) | 1277 (64%) | 1233 (71%) | 1205 (77%) | 2066 (84%) |
| Comments | 370 (23%) | 462 (23%) | 313 (18%) | 216 (14%) | 199 (9%) |
| Complaints | 242 (15%) | 235 (12%) | 172 (10%) | 131 (8%) | 171 (6%) |
| Formal complaints | 5 (1%) | 21 (1%) | 26 (1%) | 15 (1%) | 26 (1%) |
| Total | 1602 | 1995 | 1744 | 1567 | 2493 |

Table 3: Breakdown of all feedback received during the last 5 years

Unsolicited feedback

Within our feedback figures, we include feedback gleaned from evaluation surveys. If we remove survey data, we received a total of 809 items of unsolicited feedback (eg people complete a feedback card or email us). Of these, 452 were positive and 158 were negative.

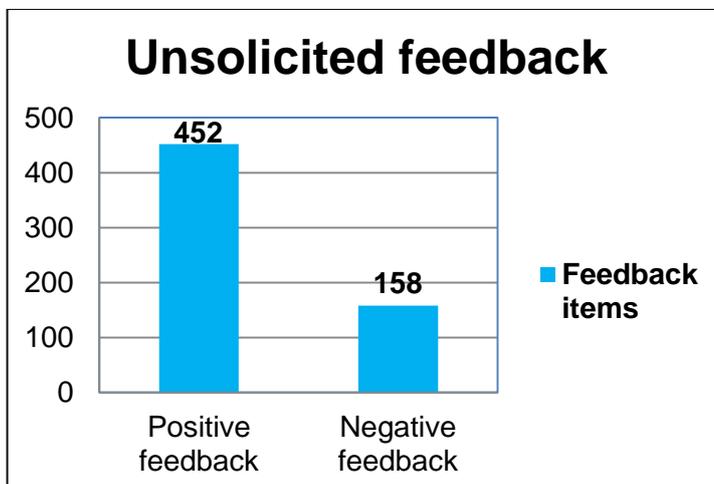


Figure 4: Number of positive feedback items versus negative item

Compliments

The following areas of our work have received the strongest positive feedback during 2015:

- **Parkinson's Local Advisers**

Just over half of the compliments received were in relation to our Parkinson's Local Adviser Service, with some service users referring to these services as "first class". Moreover, many users reached out specifically to tell us about the positive changes our advisers had made to their lives.

- **Information Resources**

Many users told us that our written and audio-visual resources are very "clear", "empowering" and "optimistic" in tone. We also received positive comments about our quarterly magazine, The Parkinson.

- **Individual Giving Appeals**

Our Individual Giving Supporters thanked us specifically for sending out a DVD of 3 different talks given by Parkinson's UK researchers, as well as an introduction by our Director of Research and Development, Arthur Roach. Many supporters expressed that this was a clearer and easier to follow method of communication in contrast to written reports.

- **General services**

People in contact with us have shared excellent feedback about our all round staff service as well as positive thoughts about their general view of the charity.

- **Volunteering**

Our volunteers have provided great feedback about their experiences as a volunteer and the support they've received (including positive comments about our new induction for volunteers, attending local volunteer forums, etc).

- **Website, forum and social media**

Users have expressed how supportive they've found sharing their experiences with others on the forum as well as having our Facebook page and website to turn to for further information.

- **Research Support Network**

People have thanked us for arranging our Research Supporters' Conference and have also shared some positive feedback about our Progress magazine and Brain Bank.

- **UK Parkinson's Excellence Network**

Healthcare professionals have reached out to congratulate us with the launch of our new Network. The resources we have produced for the Network have also received some great feedback since.

- **Involvement activity**

People who have listened to members of our staff talk at Local Groups and other events have found these sessions to be very "encouraging" and "inspiring". For example, a total of 29 students shared positive comments about a session delivered by our User Involvement Advisers at Royal Holloway University. These sessions were arranged by the University to aid students' understanding of Parkinson's. And a total of 52 of the students who attended strongly recommended that these sessions should be repeated in the future.

Complaints

Formal complaints are complaints:

- that have been escalated from an informal (ie initial) complaint
- where a person has explicitly told us they would like to make a formal complaint
- that have been sent directly to the Chief Executive and/or Board of Trustees

The total number of formal complaints in 2015 was 26. Of these, 20 were upheld, meaning we did not meet our target range of having no more than 20% of complaints upheld.

| Formal complaints | 2011 | 2012 | 2013 | 2014 | 2015 |
|---|------------|-------------|------------|------------|------------|
| Fully upheld | 2 | 2 | 5 | 5 | 20 |
| Partially upheld | 3 | 3 | 4 | 0 | 4 |
| Not upheld | 0 | 16 | 17 | 10 | 2 |
| Total | 5 | 21 | 26 | 15 | 26 |
| Percentage upheld target = <20% | 40% | 9.5% | 19% | 33% | 77% |

Table 4: Breakdown of formal complaints

In 2016 we will be working with staff and managers on better resolving complaints in the first instance, avoiding them becoming formal complaints.

Overall, in 2015 there was a slight increase in the total number of complaints in comparison to 2014 – a total of 197 complaints were recorded in 2015 against 146 in 2014. Nevertheless, this figure was still lower than 2012 and 2013 – a total of 247 complaints were recorded in 2012 and 256 in 2013.

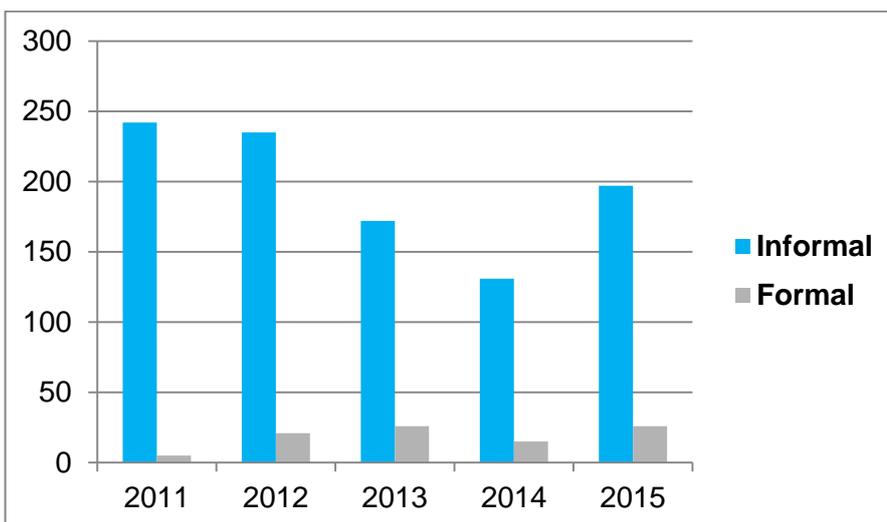


Figure 5: Trends in complaints over the last 5 years

Complaint Themes

In 2014, a vast majority of complaints we had received were in relation to dissatisfaction with repeated fundraising activities or content. This was not the case in 2015.

A breakdown of the key complaint themes from 2015 is provided below.

Formal complaints

The most reoccurring formal complaint themes were:

- non removal from the mailing database
- not receiving a thank you letter after donating to the charity.

In order to minimize such issues in the future, there will be further database work taking place this year. Moreover, our Supporter Services team had experienced a huge backlog in processing donations and sending thank you letters in early 2015. This has since been resolved and the team has also recently been restructured, which will lead to further improvement in processes.

| Complaint Theme | No. | Upheld |
|---|-----|--------|
| Non removal from the mailing database | 9 | 7 |
| No thank you letter after donation | 6 | 6 |
| Slow/no staff response | 3 | 3 |
| Poor customer care (staff behaviour) | 3 | 2 |
| Wrong information on thank you letter | 1 | 1 |
| Dissatisfaction with Local Adviser's advice | 1 | 0 |
| Dissatisfaction with donation processes | 1 | 0 |
| Dissatisfaction Brain Bank processes | 1 | 1 |
| Repeated mailings | 1 | 0 |

Informal complaints

| Complaint Theme | No. |
|---|-----|
| No thank you letter after donation | 14 |
| Dissatisfaction with service (processes) | 10 |
| Disliked Marketing campaign | 9 |
| Poor customer care (staff behaviour) | 8 |
| Slow/no staff response | 7 |
| Technical Issues with website/forum/Shop/etc | 6 |
| Wrong information on thank you letter | 6 |
| Error in membership lists for Local Groups | 6 |
| Complaint about products from the Shop | 5 |
| Dissatisfaction with information resource | 4 |
| Lack of activities/services in local area | 4 |
| Repeated fundraising mailings | 3 |
| Lack of support from charity for creative outlets | 2 |

Learning from complaints:

- **Unsatisfactory customer care**
In order to better monitor and improve our customer care standards across the charity, we will be implementing mystery shopping exercises in 2016. These exercises will specifically target teams that have received a high number of complaints in this area over the past few years.
- **Monitoring service quality (Parkinson's Local Adviser Service)**
By the end of 2016, our service managers will have gone out in the field to observe the practice of all Local Advisers in their team. Managers will also complete a review record for each member of staff to demonstrate how they are working to the service framework and guidelines, including guidance on medication. Any cases that are identified by managers to support the learning needs of Local Adviser's will be discussed on a quarterly basis in team meetings.
- **Repeated fundraising mailings**
We have reduced the volume of fundraising appeals for supporters who have reached out to tell us that they have found the existing number of appeals counter-productive.
- **Further work to improve our database**
We will be carrying out further database work during 2016 in order to resolve key issues that have been occurring on our database when removing supporters from further mailings.
- **Please also see Appendix 1 – “You said, we did”.**

Comments/suggestions

Below is a breakdown of some of the comments/suggestions we received in 2015.

"Although this year's Parkinson's Awareness week campaign got lots of media attention, I really feel you missed a trick in asking people to try to understand the daily challenges people face. I subscribed to 'Up my friendly' but as each daily challenge came through I felt there was a real gap in linking this to the lived experiences of people with PD. For example, the suggestion to help with someone's shopping might have been more powerful with a link to a video or interview with someone talking about what it's like when you can't get your change out of your purse at the check out and people in the queue get impatient with you."

Action: Based on this and similar feedback received, particularly from local groups, the 2016 Parkinson's Awareness Week campaign was very different and much 'simpler' in concept and messaging. It focussed solely on the needs of people affected by Parkinson's and the impact of receiving a diagnosis of Parkinson's. It also highlighted the support that Parkinson's UK can offer.

"More magazine articles about people who have Parkinson's but must cope alone - no family support."

Action: The Spring 2016 issue of The Parkinson magazine had a feature about living alone and advice which addressed some of the challenges living alone can present. It also featured a story of a person affected who lives alone. The magazine aims to present personal life stories from the full spectrum of people affected by Parkinson's.

A supporter contacted the charity with regards to 'receiving' support in publishing/promoting a poetry book and feels that the charity is not very supportive in such matters.

Action: Based on this comment and a history of similar ones, people who are creative writers were invited to join a working group to consider what the charity can do to better support this type of creativity of people affected by Parkinson's. See 'You said, we did'.

"You know what would be really good?! A local "keep fit" class designed specifically for people with Parkinson's - I notice we join these for older people and of course the exercises aren't quite right..."

Action: Area Development Managers, with local teams and volunteers, are carrying out mapping exercises that will identify the gaps in activities offered around the UK. Exercise has been identified as a priority area for activities which should be available for people affected by Parkinson's wherever they are. This will be an important focus for us moving forward.

"We need more awareness of problems e.g. leave support leaflets at surgeries and chemist, use local media and radio."

Action: The Turn to Us campaign aims to reach everyone affected by Parkinson's through targeted advertising in health settings and is supported by Information Volunteers. The volunteers target health care settings such as GP surgeries, pharmacies, hospitals and care homes with Turn to Us posters, leaflets and business cards. In addition, raising awareness of Parkinson's with the general public is a key focus of our current strategy.

"I am appalled that there is not even a skeleton service over the Christmas and New year period, not even a call back service ... Maybe some funds could be set aside for providing such cover in future years?"

Action: The helpline does have a skeleton service over Christmas, opening for 4 hours every day over Christmas except Christmas Day, Boxing Day and New Year's Day. It remains closed on Sundays throughout this period.

A supporter has contacted us to express his concerns with regards to repeated requests for research funds. He appreciates that it is beneficial to contact people who have previously donated, but feels that the continued requests become annoying and counter-productive after a while.

Action: Our supporters can opt out of receiving our fundraising materials and we reduce these for anyone who contacts us. A specific project on email and contact preferences is currently under way.

Appendix 1 – You said, we did 2015

Set out below are some examples of how user feedback was taken on board during 2015:

| You said | We did |
|--|--|
| <p><i>Raising public awareness</i></p> <p>Many of you have told us about negative experiences you've had due to the low public awareness of Parkinson's symptoms. For example, lack of patience from people at places like rail stations and supermarkets, being stared at in restaurants and considered to be drunk. In fact, our research found that an estimated 69,000 people affected by Parkinson's experience rudeness and hostility from the public (YouGov 2015). You told us that raising public awareness of Parkinson's should be a priority.</p> | <p>In 2015 we developed and piloted awareness raising sessions for customer-facing organisations.</p> <p>Before the pilot we tested the sessions with pub staff from three Fuller's Inns, training staff at Transport for London and shop floor staff at BHS. This helped shape the pilot which ended on 29 February 2016. In addition to the three organisations who helped test it, we've had 37 organisations sign up to the pilot through the website. This year, we'll continue to analyse the feedback, which will then help shape and expand the final versions to different types of public-facing organisations, including call centres.</p> <p>The sessions fit alongside the organisations existing staff training programmes so staff can learn more about Parkinson's and the practical ways they can support customers and colleagues with the condition.</p> <p>The session is pre-narrated and self-sufficient so an organisation's in-house trainer can easily deliver the session without requiring any Parkinson's expertise.</p> |
| <p><i>Being diagnosed</i></p> <p>Many of you told us about the negative impact your diagnosis appointment had on you. You said that being diagnosed is made all the more difficult by a lack of information and support about what a diagnosis means and what you can do to take control. You told us how the negative language sometimes used during diagnosis can have a detrimental impact on you.</p> | <p>Based on what you told us, this work has been carried forward through the Excellence Network. We've produced guidance for health professionals on how they can improve the experience of diagnosis. The resource gives tips on how to structure services, improve communication and increase access to information so that the experience of being diagnosed can be as positive as possible. This focus on diagnosis will continue, with strong involvement from people affected by Parkinson's.</p> |
| <p><i>Nurse call-back times (helpline)</i></p> <p>Our helpline's evaluation survey in 2015</p> | <p>Even though we regularly were getting back</p> |

| | |
|--|--|
| <p>confirmed that you value the service, with 97% of people who responded saying they would recommend it to a friend. But some of you also said that sometimes you found it frustrating to be told a nurse call-back could take up to 48 hours.</p> | <p>much sooner than 48 hours, we have now changed the standard nurse call back time to within 24 hours. For many, this will mean a call back on the same day.</p> |
| <p><i>Involving you in research</i></p> <p>In 2014 we asked members of the Research Support Network (RSN) various questions related to being part of the Network. Members told us that one area we should focus on more was providing more opportunities for them to work alongside researchers to help shape Parkinson's research.</p> | <p>So, during 2015 we have developed our Patient and Public Involvement pilot programme, where we have held and supported 8 meetings partnering researchers and people affected by Parkinson's across the UK. At these meetings all people affected by Parkinson's have received 'Research Induction' training from research staff members and then have had an opportunity to comment on and shape vital Parkinson's research.</p> <p>And in order to raise awareness amongst Parkinson's researchers about the benefits of involving people affected by Parkinson's, we developed our 'Patient and Public Involvement: Resource for researchers'. As the first resource of its kind, it has been very well received and shared by over 60 universities and organizations across the country and internationally, raising Parkinson's UK's profile as leaders in involvement.</p> |
| <p><i>Creative writing and poetry</i></p> <p>Creative writing and poetry is something that many people affected by Parkinson's enjoy doing. It's another way to take control for many. Some of you told us we could do more to support and promote this creative outlet in people affected by Parkinson's.</p> | <p>In late 2015 we asked for creative writers affected by Parkinson's to come forward and work with us on developing ideas for better ways to support creative writing. The first meeting of this working group took place in February 2016. We hope that we will soon be able to let everyone know about the new ways in which we are promoting and supporting creative writing.</p> |