

## Annual report on user feedback 2013

### Introduction

This report gives an update on the key themes received through our customer feedback mechanisms during 2013. A full breakdown of all feedback received is available on request. This paper also includes a summary of the impact of the new user involvement team, given that they have been in place now for one year.

### Definitions

The term 'feedback' includes:

- comments/suggestions – what people think we can change
- compliments – what people think we have done well
- complaints – what people think we have done wrong

Formal complaints are complaints:

- that have been escalated from an informal 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

### Breakdown of feedback received in 2013

| Feedback          | 2011         | 2012         | 2013         | Difference  |
|-------------------|--------------|--------------|--------------|-------------|
| Compliments       | 985 (61%)    | 1,277 (64%)  | 1,233 (71%)  | -44 (+7%)   |
| Comments          | 370 (23%)    | 462 (23%)    | 313 (18%)    | -149 (-23%) |
| Complaints        | 242 (15%)    | 235 (12%)    | 172 (10%)    | -63 (-2%)   |
| Formal complaints | 5 (1%)       | 21 (1%)      | 26 (1%)      | +5 (0%)     |
| <b>Total</b>      | <b>1,602</b> | <b>1,995</b> | <b>1,744</b> | <b>-251</b> |

| Formal complaints upheld |          |           |           |
|--------------------------|----------|-----------|-----------|
|                          | 2011     | 2012      | 2013      |
| Fully upheld             | 2        | 2         | 5         |
| Partially upheld         | 3        | 3         | 4         |
| Not upheld               | 0        | 16        | 17        |
| <b>Total</b>             | <b>5</b> | <b>21</b> | <b>26</b> |

## Major themes from 2013 feedback

### Formal complaints

We received a total of 26 formal complaints. Of these complaints, five were upheld and four were partially upheld. The vast majority were received from the local group network who were unhappy about:

- financial and fundraising processes including delays in receiving transferred funds, receiving out-of-date membership information and the level of financial paperwork needed to be completed by groups
- delays in receiving orders via CDL, our distributors
- the Stratford AGM/Conference no longer being an annual weekend event and the general organisation of the 2013 event
- fundraising legacy appeals (telephone calls to warm supporters)
- unsuccessful Honorary Lifetime Membership award applications

In late 2012, the Chief Executive decided that the definition of a formal complaint should include those that were sent directly to his office and/or the Board of Trustees. The 2013 formal complaint figures reflect this. If we had assessed 2013 formal complaints in the same way as 2012 we would have recorded 16 fewer formal complaints, bringing the figure to a total of 10.

### Informal complaints

People expressed dissatisfaction in relation to the following areas (the number in brackets shows the number of times the feedback was raised):

- lack of support received at a local level (24)  
(through staff (four), unfriendly/unsupportive groups (eight), local services eg neurologist (two), misunderstanding charity decisions that relate to the group network (four), events eg cluster meetings (two), and opening hours/slow response of the helpline (four))
- the *Getting to know you* volunteering form (23)
- targeted mailings/telephone calls used for our fundraising (20) against 403,081 individual giving mailings sent out and 7,200 legacy fundraising calls made
- communications with donors eg mailings sent to people who had died or no thank you/acknowledgement for donations received (18)
- general staff service/lack of response resulting in customers not feeling supported by the charity (16)

The proportion of positive to negative feedback for the year was 14:86% against a target of 25:75%.

## Action taken

| Issue   | Actions taken   |
|---|---|
| <i>Getting to know you</i> volunteering form              | FAQ produced for the local group network explaining the process, costs and rationale behind this volunteering project                             |
| Fundraising communications                                | Intensive work on the database continues  |
|   |   |
| Issue   | Actions to be taken   |
| Lack of support received at a local level                 | The new strategy will help us work differently and better, offering more opportunities for choice and different ways for people to engage with us |
| General staff service/lack of response                    | Increase communication around our customer care policies and processes to staff   |
| Fundraising mailings/telephone calls (to warm supporters) | Article in <i>Network News</i> explaining why we use this type of fundraising and how people can opt out etc                                      |

Please also see Appendix 1 – *You said, we did* 2013.

## Comments/suggestions

In appendix 2, we've attached a list of some of the suggestions we were sent. We received comments on the following key themes:

- how to improve/adapt the content of our resources (26), for example more information about driving, hallucinations and swimming
- fundraising events and various suggestions about, for example, enhancing information and the staff support provided, and on new merchandise to sell such as fleeces, sweatshirts, shopping bags (24)
- improving the *Getting to know you* volunteering form (13)
- lack of care/support in health and social care settings (10)
- the need to raise the charity's profile along with awareness of the condition (10)
- ideas for new trading merchandise and adapting existing products, including information resources, daily living aids and promotional items. (7)

In addition, we used an external agency to capture lots of feedback about the future of the local group network at the May Together events (756). These figures are not included in this report.

## Compliments

There was strong positive feedback about the following areas:

- information resources (141)
- information and support – helpline, information and support workers (ISWs) and nurses (132) (excludes ISW survey)
- fundraising events – support/advice/information (121)
- new website and forum (48)
- general progress and view about the charity (37)
- research – speaking events and *Progress* magazine (32)
- trading and merchandise products (24)
- general all-round staff service (23)
- public awareness Everyday campaign (22)
- Volunteer educator workshops (15)
- Parkinson's Awareness Week materials (13)

## Communicating the feedback and actions for improvement

We plan to make a number of improvements to the way we communicate and manage our feedback. This follows our last assessment with the Customer Service Excellence ® standard and builds on the changes we made in 2012. We will:

- raise the profile and importance of feedback on our intranet Staff Central through more regular blogs and reminders to staff to send feedback centrally
- review and update our feedback/complaints process and promote it to all staff
- communicate more directly with directors on formal complaints and present feedback reports at directors' meetings more regularly
- make further updates to our website so that detailed and general performance and satisfaction information is readily available, as well as more visually appealing
- review the information about service expectations that's sent out when first visiting clients with the Support and Local Groups directorate
- update the information and support leaflet with our customer care statement
- approach other charities to discuss a more suitable way of capturing appropriate benchmarking information, and possibly set up a 'benchmarking' group

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March 2013

## Appendix 1 – You said, we did 2013

Set out below are some examples of how we took user feedback on board:

| You said   | We did  |
|--|---|
| <p>You mentioned that there was not enough information about Parkinson's, to help educate people and improve understanding of the condition, in public places such as hospitals.</p> | <p>In 2012, our Turn to us campaign led to more than 150,000 leaflets being picked up at GP surgeries and pharmacies by members of the public. This year, we asked supporters across the UK to help us place Turn to us literature and posters in their local GP surgeries, pharmacies, care homes or hospitals. By the end of 2013, 82% of people affected will have had the chance to see our materials. Next year, our focus will be reaching those in remote and rural areas.</p>                         |
| <p>Some of you said that our workforce should reflect/represent people living with Parkinson's more strongly.</p>  | <p>The charity now employs three members of staff who are directly affected by the condition. Their roles include championing your views and making sure people affected by Parkinson's are involved in all of the charity's work.</p>  |
| <p>You shared concerns about the expense and rationale behind the <i>Getting to know you</i> volunteering form.</p>  | <p>We produced some FAQs for anyone interested in finding out more details about the project. This includes information about the cost and why it was necessary to improve support for volunteers, and about the process of developing and piloting the questionnaire. In the future, new volunteers will complete an application form so that this kind of questionnaire won't be necessary again.</p> <p>For a copy of the FAQs, contact <b>volunteering@parkinsons.org.uk</b> or <b>020 7963 9328</b>.</p> |
| <p>You felt there was a lack of understanding among some members of staff concerning the day-to-day, practical needs and "problems" of people with Parkinson's.</p>                  | <p>Our user involvement team has provided guidelines for staff on the practical needs/issues that should be considered when involving service users in our work.</p>  |
| <p>Some of you were unhappy about being contacted by our fundraising agency about leaving gifts in your wills.</p>   | <p>We contacted you individually via an agency as they have the skills and resources to undertake this kind of fundraising activity. Gifts in wills account for more than 40% of our annual income (£8.6m in 2012) and help</p>   |

|   |  |
|---|--|
|   | <p>secure our long-term future. All the gifts we receive, whether large or small, make a huge difference to our work.</p>  |
| <p>You gave really positive feedback about local group visits to the UK Office.</p> | <p>We will continue to organise these popular events, which give you a chance to meet staff, find out about their work and ask lots of questions. If you'd like to visit the UK Office, please contact the External Relations Administrator on <b>020 7963 9381</b> or email <b><a href="mailto:feedback@parkinsons.org.uk">feedback@parkinsons.org.uk</a></b></p> |

## Appendix 2 – selection of suggestions 2013

|   |
|---|
| <ul style="list-style-type: none"> <li>• Ref Get it on time: "I think the campaign should try to get the information included in the 'cautionary and advisory labels for dispensed medicines' listed in the British National Formulary (BNF)."</li> </ul>   |
| <ul style="list-style-type: none"> <li>• "...You are missing a trick by not having a tear-off bit to return with donations and Gift Aid declarations [in <i>The Parkinson</i>]."</li> </ul>   |
| <ul style="list-style-type: none"> <li>• Ref resources: "Can't we make more use of mobile phones to raise awareness and understanding of Parkinson's? Can't we provide more information on there?"; "Our publications are brilliant but we have too many of them. It feels like we're creating publications for the sake of it. Can we hold off from producing more publications for a while?"; "The leaflets we produce are a problem to store because they are all different sizes."</li> </ul>       |
| <ul style="list-style-type: none"> <li>• Ref 'Give me time' badges: "Do you have anything with same/similar wording that could be used as a notice on the door?"; "I have doubts about the Give me time badge as it may broadcast disability and vulnerability to the wrong people...I'd suggest a shiny enamelled badge in ribbon design in Parkinson's blue eg a celtic knot...There could be a link with sport eg a ball, golf, cricket...Ladies would like a bit of glitz on theirs."</li> </ul>    |
| <ul style="list-style-type: none"> <li>• Ref Christmas concert: "...In the programme, the words for the communal carols were printed – it would have greatly enhanced our enjoyment if the word for the pieces performed by the choirs and soloist were also in the programme...could we have the words in the programme so that those at the back can understand the meaning of the works?"</li> </ul>   |
| <ul style="list-style-type: none"> <li>• Ref fundraising cold calls: "...We need a message from (UK head office) to say this is a Parkinson's UK initiative and explain to members why we're doing this."; "...Some of our members are a bit vulnerable and hopefully this is taken into account before calls are made..."</li> </ul>   |
| <ul style="list-style-type: none"> <li>• "...I am wondering if Parkinson's UK has explored Parkinson's-friendly income sources for the transition from employment to retirement, or would you consider doing so in future?...Is there scope for Parkinson's UK to explore more Parkinson's-friendly ways of defining and recruiting for jobs, consultancies or distinct pieces of work?...Would enable highly skilled and motivated people to make a professional contribution the charity."</li> </ul> |
| <ul style="list-style-type: none"> <li>• "...Could key role of branch chair be made less onerous?...How could committee functions be best redefined, rotated, shared, delegated?...Could Parkinson's UK explore/promote Parkinson's-friendly leadership models that take account of limited quality time, fragile self-confidence, fluctuating health issues?...Are there more appropriate ways of working as a Parkinson's group other than forming a committee?"</li> </ul>                           |
| <ul style="list-style-type: none"> <li>• "...Can we get cheaper products via Microsoft for branch computers?"</li> </ul>  |
| <ul style="list-style-type: none"> <li>• "As a branch we do not feel connected to head office. We would like to see more people from head office at our meetings. Staff should become more involved in branch activities – staff should work as volunteers one day per month."</li> </ul>   |
| <ul style="list-style-type: none"> <li>• "Communications to branches should always include: who else is receiving the communication (so no action duplicated), who to contact for queries, what the exact action/request is ie is it for info to share with the committee, to share with all members; and send an e-copy so it can be emailed to members"</li> </ul>  |
| <ul style="list-style-type: none"> <li>• "Head office is very ambitious in what we want to do as a charity but to deliver it we need volunteers. Most of us are already stretched, over tired, with too much responsibility...Most of us are carers too. We don't have the time or capacity to do everything HQ tell us to do. We can't cope."</li> </ul>   |
| <ul style="list-style-type: none"> <li>• "...Provide an info package for new people attending groups to help bring them up to speed with the ethos of Parkinson's UK. People tend to talk over your head and use short forms/jargon/initials you don't know."</li> </ul>  |

- "...Consider having a volunteer service available to work with people who have speech difficulties linked to Parkinson's – doing exercises, prompt for a loud voice and provide a communication partner for extra practice."