

Annual report on user feedback 2014

Introduction

This report gives an update on the key themes of feedback received through our customer feedback mechanisms during 2014. A full breakdown of all feedback received is available on request.

Definitions

The term '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

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

Activity in 2014

Our feedback mostly focusses on aspects of our support services, resources, supporter care and fundraising activity and campaigns. For context, in 2014:

- the helpline answered 22,000 phone calls;
- the information and support service supported approximately 14,000 people;
- as an example, in Q4 2014, there were approximately 418,000 pieces of fundraising communication with supporters (mail = 165,000 from 19 Campaigns; phone = 3500 contacts from three Campaigns; emails = 250,000 from 6 Campaigns).

Breakdown of feedback received in 2014

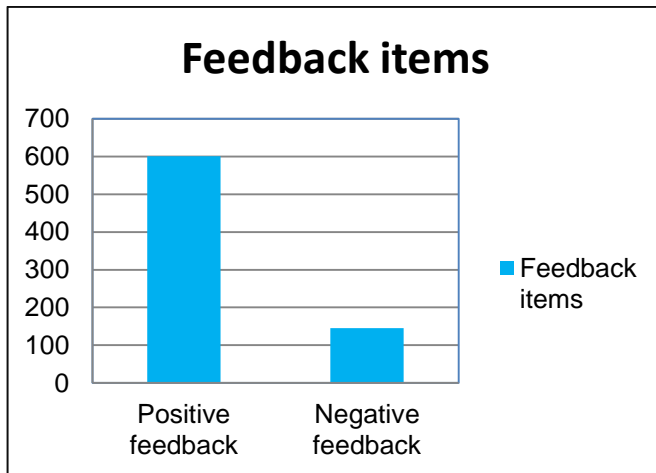
In 2014, we received 962 items of feedback in total of which, 601 items were positive and/or complimentary.

Feedback 2014	Q1			Q2			Q3			Q4		
	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sept	Oct	Nov	Dec
Comments	11	9	21	41	12	16	66	15	0	13	4	8
Compliments	24	35	128*	43	24	25	197**	54	19	5	22	25
Complaints	9	8	21	7	8	5	10	10	19	9	17	9
Formal Complaints	1	3	0	1	0	0	0	1	2	1	3	2
Total	45	55	170	91	44	46	273	80	40	28	46	44

* includes 100 pieces of feedback after a training session

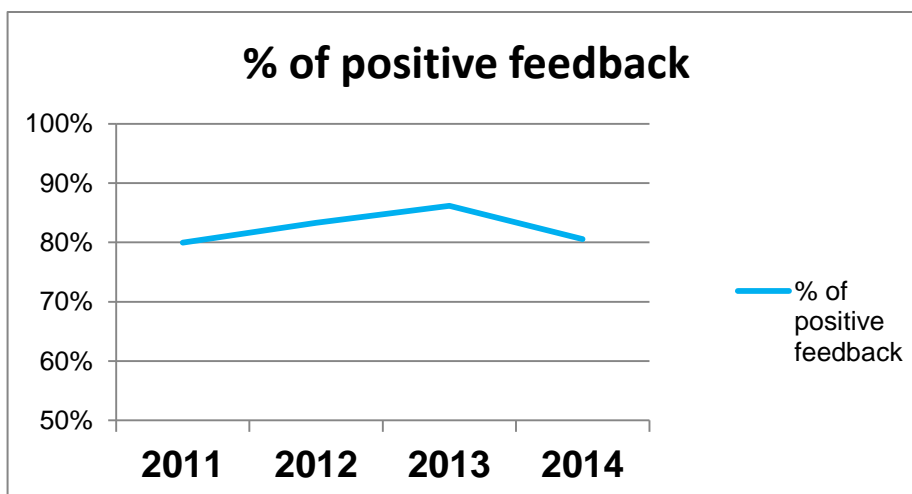
**includes 117 helpline survey respondents

The percentage of positive feedback compared to negative feedback was 81% (target =>75%)



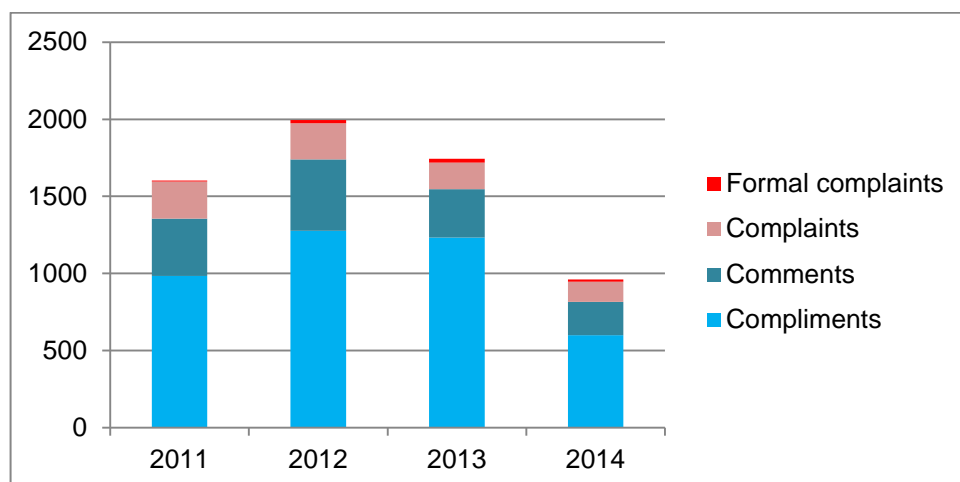
Comparison to previous years

Compared to 2013, our percentage of positive to negative feedback decreased slightly although it continues well within our target range.



Year	2011	2012	2013	2014
Target	< 25%	< 25%	< 25%	< 25%
Actual	20%	17%	14%	11%

Compared to previous years, the total number of feedback items has decreased.



Feedback	2011	2012	2013	2014
Compliments	985 (61%)	1277 (64%)	1233 (71%)	601 (62%)
Comments	370 (23%)	462 (23%)	313 (18%)	216 (22%)
Complaints	242 (15%)	235 (12%)	172 (10%)	130 (14%)
Formal complaints	5 (1%)	21 (1%)	26 (1%)	15 (2%)
Total	1602	1995	1744	962

The reasons for this reduction in total number of feedback items in 2014 include:

- Previous years' figures have included additional survey results (for example, 572 ISW survey respondents were included in April 2013, whilst the survey results for 2014 have not yet been made available).
- Previous years have included significant numbers of feedback from Together events and a high profile awareness campaign.
- Issues commented on widely in previous years, related to significant organisational/ governance issues, including safeguarding, volunteering and volunteer 'Getting to know you' forms.

Compliments

There was strong positive feedback for the following areas:

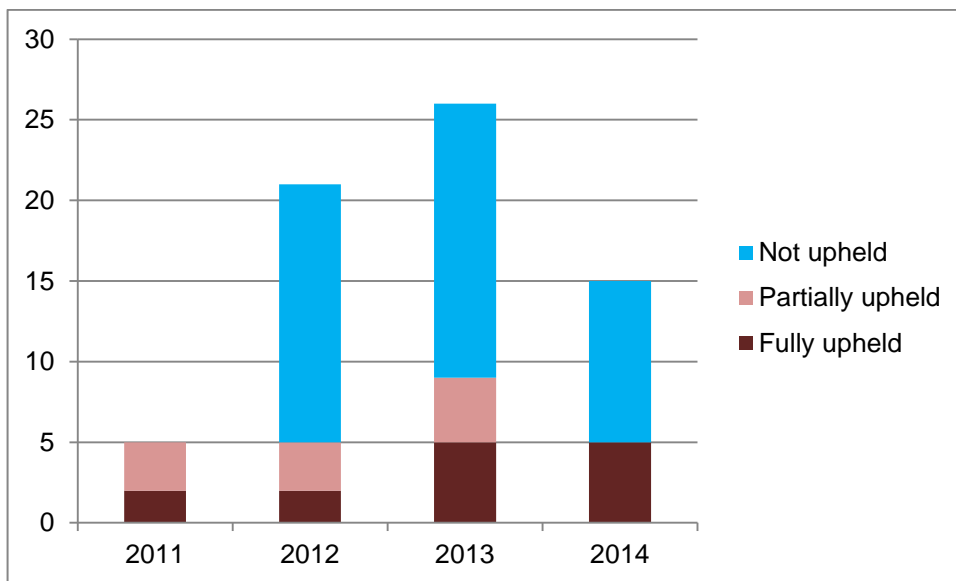
- Information resources (76)
- Information and support – helpline, ISWs, etc (189) (incl 117 helpline survey responses)
- Training and awareness events (105)
- Events (91) eg Symfunny; fundraising runs
- Fundraising mailings (5) eg happy to support; good luck with your work

- General all round staff service (6)
- User-involvement activities (24) eg focus group and visits to 215
- Website and forum (20)
- Awareness week campaign and materials (24)
- General progress and view of the charity (26)

The total number of formal complaints in 2014 was 15.

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

We received fewer complaints in 2014 compared to the previous two years.



As shown in the table and graph above, 2014 was a year positive year in that complaints were reduced compared to 2013 and 2012. However, proportionally, a third of complaints in 2014 were upheld meaning we did not meet our target of having no more than 20% of complaints upheld.

Complaint themes

Formal complaints

In 2013, the vast majority of complaints were received from the local group network but this was not the case in 2014.

We received a total of 14 formal complaints, of which five were upheld. Themes included:

Major feedback themes 2014

Formal complaints

We received a total of 15 formal complaints. Of these, five were upheld. In 2013, the vast majority of complaints were received from the local group network but this was not the case in 2014. Main themes were:

- Unsatisfactory customer care (4)
- Lost / uncashed cheques (1)
- Repeated contact for fundraising activity (2)
- Use of Steve Ford's computerised signature on fundraising letter (1)
- Delay in contact from Education and Training Officer (1)
- Complaint about a Branch Volunteer Support Officer (1)
- Branch committee member resigning due to feeling badly treated by staff (1)
- Individual seeking definitive guidance on use of an intravenous drug (1)
- Dissatisfaction with financial arrangements between a branch and a support group (1)
- Complaint from supporter about a branch committee member (1)
- Complaint from researcher regarding our "bureaucratic processes" (1)

Informal complaints

The main themes of informal complaints included:

- Dissatisfaction with repeated fundraising activities or content (27)
- Issues related to costs of and unpaid postage on magazine mail-out (8)
- Dissatisfaction with marketing campaigns (4)
- Complaints about access difficulties at a focus group meeting (1)
- Unsatisfactory customer care (5)
- Delayed/lack of response (14)
- Delayed cashing of cheques (3)

Action taken relating to most significant complaints

Issue	Action taken
Complaints relating to poor customer care from supporter services	New 'virtual call centre' telephone software in use, will allow for better monitoring of call volumes, proportion of answered and

	lost calls, staff occupancy rates, etc. A set of KPI's will also be established to track and monitor Supporter Services Team activity highlighting peak demand and where resources are stretched. Plans for improved fundraising complaints management and customer care training being finalised.
Fundraising communications	Work continues relating to our database – we are also looking to contextualize the ratio of complaints to activity to establish a baseline and allow a comparison from month to month.
Outsourced fundraising cold calling	All call centre staff are trained by both charity employees and a person with Parkinson's, as standard. All calls are recorded so we are able to provide feedback on complaints. Calling is monitored and evaluated throughout the campaigns.
Lack of rooms with good access at London office.	Because of the decreasing space at the office, we have lacked a ground floor meeting room since 2013, making it difficult for some to meet on the premises. We now have plans for a ground floor meeting room, which will allow easier access (eg wheelchair users). The room will be available from mid 2014.

Please also see Appendix 1 – ‘You said, we did’ 2014.

Comments/suggestions

Attached in Appendix 2 is a list of some of the suggestions that were sent in. In terms of key themes, we received comments on:

- how to improve/comments on content of our resources (31) eg key fob instead of Alert Card; more multi-media resources
- Fundraising events (46) eg quality of vests; post-race reception
- views on fundraising campaigns (9) eg prefer to not be called
- membership (5) eg receiving multiple items for couple in a household; difficulties donating
- Ideas for support (7) including improving support for people at later stages of Parkinson's, nursing home training; peer support
- Parkinson's professionals (8) including need for more nurses; improved awareness and screening of ICB, more liaison with branches
- Awareness Week (12)

Appendix 1 – You said, we did 2014

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

You said	We did
In 2013 we asked you, as a person affected by Parkinson's, what were the three most important things that you felt would help improve your life, so that we could put the needs of people with Parkinson's at the centre of our work. We received over 700 items of feedback from you, by mail and/or in person at focus groups.	In late 2013 we collated and analysed all of your feedback and spent much of 2014 developing the charity's new strategy for Parkinson's. You told us what you felt was most important to you and your life with Parkinson's. We are now ready to launch our 2015-2019 strategy based on what is most important to you.
A cure and developing better treatments - you told us that not only was it important that we focus on finding a cure for Parkinson's, you also want there to be improved treatments available that can better control symptoms day-to-day.	So this is one of the aims of our new strategy. <ul style="list-style-type: none"> • We'll provide leadership to the international Parkinson's research community – bringing people together to focus on the most urgent challenges. • With academic, industry and regulatory partners we'll speed up the process of developing new treatments. • And we'll work with other organisations, professionals and people affected by Parkinson's to drive better clinical research.
Better services - you told us you needed improved multi-disciplinary health services, and health professionals who listen to you and understand your needs.	So we created and launched a UK-wide Parkinson's Excellence Network, bringing together the passion and expertise of leading professionals, the voice of people affected by Parkinson's and the strategic leadership and resources of Parkinson's UK. We believe that working in partnership with health and social care professionals, we will drive sustainable improvement in services.
Taking control - you told us that feeling 'in control' for you meant having access to quality information, support and guidance around self-care. You also told us that changing the public's perceptions was important.	So, we'll raise awareness, and strive to change attitudes and behaviour, so people with Parkinson's aren't misunderstood or discriminated against. We'll empower local Parkinson's communities to provide support and life-enhancing opportunities to people affected by the condition who may be struggling to feel in control.
Employment support - you told us about your experiences at work and the sort of support you felt we should offer you and also your employers.	This year we are publishing our first guide for employers, which accompanies our existing Employment and Parkinson's booklet, which is aimed at people affected by Parkinson's. The new resource gives guidance to

	employers about how they can better support people stay in work for longer and the legal obligations they have under employment and disability rights legislations.
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Appendix 2 - selection of suggestions 2014

<ul style="list-style-type: none"> • “I feel that [the charity] has not thought about the future of people with the illness and money could have been spent on centres to allow access during the different stages of the illness. It has been a very distressing illness for me to deal with and since a cure is still a long way off it would have been so much nicer if we had had access to a home that was purpose-built for his illness and its consequent needs.” Wife of 66yo who has Parkinson's
<ul style="list-style-type: none"> • “As we are members of the association, I am continually asked for money – why isn't the general public also?”
<ul style="list-style-type: none"> • “I would prefer not to receive all the magazines, etc, as my husband at the same address [and] already gets them perhaps a tick box on the renewal form to enable an opt out would be a way?”
<ul style="list-style-type: none"> • “Why do you charge only £4 annual subscription rate? I am always surprised at the amount of info on quality paper that is sent out for £4.”
<ul style="list-style-type: none"> • “Would it be possible to have a phone day when people could see how others are getting along? Maybe one day a month?”
<ul style="list-style-type: none"> • “I am pleased to contribute to Parkinson's UK in their efforts to find a cure via research. However, I should like to see some efforts being directed towards improving the quality of life of those suffering now e.g. recruitment of PD nurses.”
<ul style="list-style-type: none"> • Parkinson's dementia factsheet: found it useful, but would like more details about medication for dementia
<ul style="list-style-type: none"> • “Good campaign video but your '5 ways people are robbed of control' doesn't include anything on how Parkinson's can affect mood / lead to depression - in my experience this is the most poorly understood and managed symptom.”
<ul style="list-style-type: none"> • A couple emailed to say that phone calls made to them “from representatives of the society to [...] make a request of us...are not welcome. We are very happy to support the society and visit the website for updates (and) receive information by post. I requested the most recent caller to remove our phone number from your database...(but) this request was not acknowledged.”
<ul style="list-style-type: none"> • “I just wondered why the ultimate goal of the charity program would be to find a cure for Parkinson's...why don't we work more on the prevention. Is there any specific reason for that?”
<ul style="list-style-type: none"> • “Both my wife and I have received separate cards thanking us for volunteering. We work hard to raise funds for your charity and others. We both feel uneasy that you have used some of the money that has been raised to send these cards. Also that there have been two mailings to the same address!”
<ul style="list-style-type: none"> • A request for a full page or two - on living alone with P.D. How to live at home when advanced.
<ul style="list-style-type: none"> • I think Parkinson's UK need to give the government proper information about PD before it's too late"

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