

Annual feedback 2012

Question for discussion: How are we taking on board the feedback received in 2012?

1. Executive summary

1. The User Involvement team systematically collates feedback from people affected by Parkinson's. This report highlights key themes and trends in informal and formal complaints, compliments and comments received during 2012. We have appended the data sheets, showing the number of comments, compliments, complaints and formal complaints received each month.

Overview

- In 2012, just under 2,000 (1,995) instances of individual feedback were received during 2012. Of these, 1,277 (64%) were compliments, 462 (23%) comments, and 235 (11%) complaints.

Feedback	2011	2012	Difference
Compliments	1,166 (60%)	1,277	+111
Comments	473 (24%)	462	-11
Complaints	301 (16%)	235	-66
Formal Complaints	6 (1%)	21	+16
Total	1,946	1,995	+49 (3%)

- A total of 1% of all feedback comprised formal complaints. The closure of Belfast Branch accounted for the biggest single focus for formal complaints. Other themes included recruitment, safeguarding, funding and focus of research, awards, the financial framework, and supporter services/customer care.
- Of the 21 formal complaints, three were partly upheld and two fully upheld. The upheld complaints relate to overpaid membership fees and a decision not to award honorary life membership. The partly upheld formal complaints related to a perceived lack of customer care, and delays in paying travel expenses.
- There were large volumes of positive feedback about specific events that participants were asked to evaluate, particularly information and support services, the London Marathon in April and Together events in September. Negative feedback and complaints tended to cover a wide

range of issues, despite a peak in September when a few Together events received some complaints alongside numerous compliments.

2. Compliments

Fundraising events

- 2.1 Activities around the London Marathon attracted many compliments and participants reported that they found the day enjoyable and well organised. There was also positive feedback about overseas treks to Jordan, Peru and Kilimanjaro

Together events (particularly Telford, Cardiff, Swindon, East Grinstead and Perth)

- 2.2 Together events attracted compliments about the mix of practical activities, discussion and presentations and how well they were organised.

Information and support services

- 2.3 The helpline received feedback suggesting the service is a real 'lifeline' run with 'professionalism and patience'. Compliments also mentioned helpline nurses who are able to explain things in a simple, clear and effective manner. A total of 94% of users who participated in an evaluation found the information and support worker service good or excellent.

The website/the forum/Facebook page

- 2.4 The forum was seen as 'a safe place to deposit our angst as well as good things' and a place to say how people with Parkinson's are feeling and thinking. People also reported positively on information, news and updates received through the website and Parkinson's social media.

Publications

- 2.5 Many Parkinson's publications attracted positive comments. Notable among this group were *The Parkinson*, *Progress* magazine ('It is very clear and gives me hope for the future'), and various information resources. A booklet for branch treasurers also received positive feedback.

Public awareness campaign

- 2.6 The public awareness campaign in December 2012 attracted many compliments. "I think that the current ad campaign with the dislocated

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tiles is truly innovative and eye-catching and gets the message of the condition across to the reader in a most effective way. I hope that it raises both greater awareness and much-needed funds. Well done."

3. Complaints and comments expressing dissatisfaction

- 3.1 Complaints and comments expressing dissatisfaction with Parkinson's UK comprised 11% of all feedback.

Supporter services

- 3.2 Key sources of dissatisfaction included lack of response or acknowledgement of donations and communications. Some complainants point out that this is not good customer service and they will not contribute again.

Individual giving

- 3.3 Fundraising letters and phone calls made by the UK Office also received some complaints from those who perceived these as excessive or offensive. There were also complaints about letters sent inappropriately due to database problems. To put this in context, there were approximately 45 (ASK ERNEST) complaints about fundraising appeal letters against 330,000 sent out.

Together events

- 3.4 We received negative feedback about events in Durham, Perth and Swindon. However, this forms a very small proportion of mostly positive feedback received.

September Together events 2012				
Venues	Attendance	Compliments	Complaints	Comments
Scotland	26	19	4	15
Northern Ireland	25	18	0	4
Wales	31	24	1	24
Telford	53	34	0	34
Exeter	24	22	0	10
East Grinstead	35	19	1	7
Durham	31	15	0	7
Swindon	19	11	3	15
Total	244	162	9	116

Safeguarding

- 3.5 There was unhappiness with the approach taken to safeguarding. “I am appalled and upset with the decision by the charity to stop all visiting by volunteers. How can we as volunteers – the people who keep the charity going – help and support people with Parkinson’s and their families if we cannot visit them?”

Awareness week

- 3.6 There was dissatisfaction about the timeliness and relevance of Awareness Week 2012 materials.

Perceptions about the UK Office

- 3.7 There were comments about UK Office wasting resources on an expanding workforce, having little everyday contact with people with Parkinson’s, and not valuing volunteers.

Support and relationships with local groups

- 3.8 There were complaints about not receiving a good service at a local level, as well as dissatisfaction at the transfer of funds, the financial framework and the way some branches are run. In addition, there were suggestions that local branches should receive training in using computers, internet and social media, and a few suggestions that UK Office staff should ‘adopt’ local branches.

4. Benchmarking

2011/12	Parkinson’s UK	Stroke	MNDA	Scope
Compliments	1,276	2,995		
Informal complaints	235	74		
Formal complaints	21	1	29	
No. of formal complaints upheld	5	1		

5. Summary of key areas for improvement and actions taken

Feedback	Action
Thanking donors	Restructuring of supporter services team
Timeliness and relevance of Awareness Week materials	Earlier delivery of materials in 2013, designed with effective involvement from local groups
Website and online community support	Web and forum redevelopment with strong user involvement

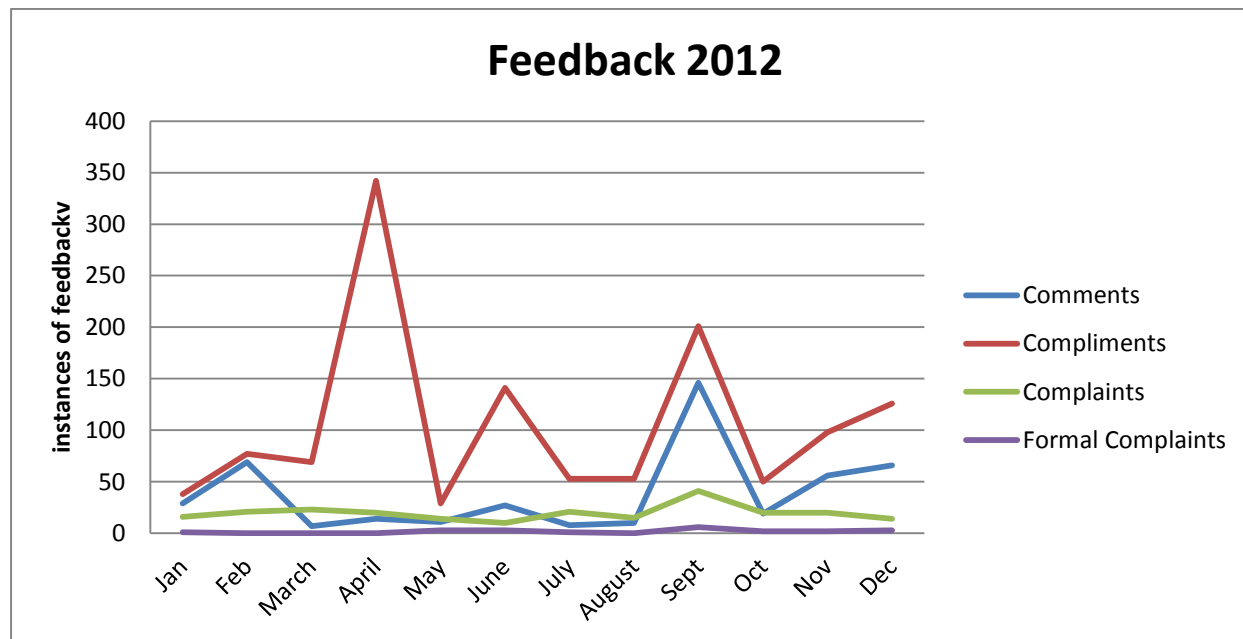
Safeguarding	Review of safeguarding approach and our communication with local groups.
Support and relationships with local groups	Developing teams with a clearer focus on support for local groups
Individual giving	Intensive work on database
Perceptions about UK Office	<ul style="list-style-type: none"> • UK Office has recruited three user involvement advisers' with Parkinson's. They will help address issues such as the language used in communications with our groups • Staff team objectives include attending a local group as part of their induction • Open day visits to UK Office
The details provided on the research studies page of our website weren't as clear as they could be	We changed the format of the studies list to make the information clearer and more consistent
You felt it was bad timing to send out the information and support worker survey in December (the Christmas/holiday season)	We sent out our 2012 survey in September instead
You were keen for there to be more of an active relationship between volunteers and staff	People affected by Parkinson's now have the opportunity to be involved in our recruitment process by sitting on interview panels

6. Communicating the feedback and actions for improvement

We will:

- raise the profile of feedback on our website so that it is more prominent and easier to find. We also aim to highlight our feedback mechanisms more, for example through our membership pack and updating the feedback postcard
- respond to feedback through our publications such as *Network News*, for example, using our monthly column. This builds on what we do already through our current annual article on feedback in *The Parkinson* magazine
- look into providing a publication that gives an annual round-up of feedback, sharing the views of people affected and the changes we've made in response
- ask the user involvement advisers to present feedback reports to directors to ensure accountability and follow-up of issues raised by the people affected

Feedback	Jan	Feb	March	April	May	June	July	August	Sept	Oct	Nov	Dec
Comments	29	69	7	14	11	27	8	10	146	19	56	66
Compliments	38	77	69	342	29	141	53	53	201	50	98	126
Complaints	16	21	23	20	14	10	21	15	41	20	20	14
Formal Complaints	1	0	0	0	3	3	1	0	6	2	2	3



FORMAL COMPLAINTS (KEY THEMES)		ISSUES RAISED	
Belfast Branch (six)		Dismay at replacing the Belfast Branch committee	
Recruitment (two)		Expenses/lost application	
Safeguarding (two)		Safeguarding framework	
Research – funding for and focus of (two)		No new drugs	
Awards (Honorary Life Membership and Waitrose Community Matters Scheme) (two)		Unsuccessful candidates	
Concerns about branch financial framework and allocation/use of funds (two)			
Support services and customer care (two)		Standard of customer care/young persons' support group	
TOTAL FORMAL COMPLAINTS (21)			
COMPLAINTS		ISSUES RAISED	
Website (five)		Logging on/updates/downloading speeds etc	
Online forum (five)		People suspended from online forum	
Trek Peru (six)		No strong leadership or support	
Parkinson's Awareness Week (14)		Lack of responsiveness and support from UK Office/online forum is not moderately well	
Just Walk 2012 and Highclere Run (two)		Not enough support/cancellation of Highclere run	
No response or acknowledgement to letters/donations (12)		Members' charitable activities/donations not been acknowledged	
Inappropriate communication (five)		Letters sent to people who have died/two mailings for one household	
Lack of support at local level (seven)		Local nurse not supportive or informed	
Lack of support from Parkinson's UK (three)		End of Sharwoods' contract is disappointing	
Local branch issues, including handling of alleged misuse of donations (seven)		Walsall Branch/money transfer from Suffolk/Christchurch/distress caused by UK Office	
Fundraising calls/letters and gifts in wills (16)		Complaints about calls/ 'begging' letters	
Safeguarding (five)		Changes to volunteering policy/ways groups can operate	
TOTAL COMPLAINTS (235)			

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KEY THEMES IN COMMENTS	ISSUES RAISED
Publications/research communications (54)	Ideas for future issues of <i>Progress</i> /Keep moving/man arrested at Olympics
Website/online communications (three)	Use online rather than posted documents
London Marathon (eight)	Would be useful to have a longer massage after the marathon
Trek Kilimanjaro (two)	Amazing experience
Open day (nine)	Speaking out and spreading knowledge/ravelling to the venue
RSN open day evaluation (18)	Spreading the knowledge and information to other groups
Trek Jordan (nine)	Better pre-trek preparation next time
Trek Peru (10)	Better information about the trek itself
Together events (98)	Distance to Together events in Telford/presentation format/should have more local branch people
Helpline evaluation (four)	Keep the helpline
Public awareness campaign (39)	Design/emphasising the positive/timing of the campaign
Financial framework/organisation set-up/use of resources (three)	Too many staff – not enough people with Parkinson's/how to improve management systems
Safeguarding (four)	Volunteering
TOTAL COMMENTS (462)	
KEY THEMES IN COMPLIMENTS	ISSUES RAISED
Trek Kilimanjaro (nine)	Excellent support
Trek Jordan (20)	Excellent experience
RSN Open Day Evaluation (10)	Positive experience
London Marathon (100)	Enjoyable and excellent support from start to finish – specially shower and massage
Public awareness campaign (20)	Well done
Parkinson's publications (60)	<i>The Parkinson; Parkinson's: the facts; Parkinson's and you;</i> and various pamphlets
Parkinson's research publications (60)	<i>Progress</i> magazine (clear and very informative) and research round-up
Website (three)	Very helpful information
Helpline/helpline evaluation (44)	Good service
Help and support (five)	Support and local groups
TOTAL COMPLIMENTS (1,277)	

Arlene Greene